

MAJOR RESEARCH PROJECT

**How do patients understand chronic orofacial pain?
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D.Clin.Psy thesis (Volume 1), 2011
University College London

Overview

Part one of this volume presents a review of the literature on the relationship between chronic pain and socioeconomic status. It examines the evidence supporting the association and considers the psychological meaning of the findings.

Part two consists of a qualitative empirical paper which samples patients with chronic orofacial pain to explore their understanding of their pain and their beliefs and fears about the causes and maintenance of their pain, both before and after an initial consultation at a specialist pain clinic.

The final section is a critical appraisal of conducting this thesis. It contains a personal reflection of conducting both the literature review and empirical paper and describes some of the obstacles encountered during the process.

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Acknowledgements

I would firstly like to thank Amanda C de C Williams for her wonderful supervision on all parts of this thesis. I have greatly valued working with Amanda due to her expansive subject knowledge and her attention to detail when reading my various drafts. Not only would this thesis not have been possible without her guidance, but I am now finishing training with a much better knowledge of qualitative research methodology, academic writing and an avid interest in the psychology of chronic pain.

I would also like to express my thanks to Jenna Love, the external supervisor of this project. Jenna's enthusiasm for the project provided valuable inspiration for me and her practical support enabled me to recruit participants from the facial pain service, without which the study could not have taken place. I am particularly grateful to her for generously devoting time and effort to checking the analysis in the empirical paper and helping me refine my results.

Lastly, I would like to convey my gratitude to the staff and patients at the facial pain clinic for enabling me to conduct my research in their service. In particular I am grateful to Joanna Zakrezwska for supporting the study and to the administrators for the invaluable practical support they provided. I also very much appreciate the time taken by the participants of the study to think about and share their chronic pain experiences. Lastly, I would like to acknowledge the Research Department of Clinical, Education and Health Psychology for funding this research.

PART 1: LITERATURE REVIEW

Associations Between SES and the Course and Consequences of Chronic Pain

Abstract

The biopsychosocial model describes a range of interacting factors impacting on the onset, experience and outcome of chronic pain but the “social” aspect has received the least attention. Whilst elements of socio-economic status (SES) such as lower income and educational achievement are associated with higher rates of chronic pain the exact nature of the relationship is unclear.

This paper reviews 13 studies which explore the association between SES and the onset, continuation and consequences of chronic pain. It found that in addition to being more likely to develop chronic pain, individuals with lower SES are also more likely to suffer greater levels of disability even when a number of variables are controlled for. Moreover, lower SES individuals are less likely to be actively involved in the management of their pain.

The epidemiological studies offered little insight into what the psychological meaning of these findings might be so links are made with the psychological research on chronic pain and the general health inequalities literature. The cognitive and emotional processes associated with social comparison may be one mechanism which exacerbates chronic pain. Less satisfactory interactions between patients of lower SES and healthcare professionals may also impact on the experience of pain. However, more research is needed which explores the psychological processes which result from inequality and which mediate the onset, persistence and consequences of chronic pain.

Introduction

This review will provide a brief overview of the relationship between chronic pain and socioeconomic status, a more extensive review of recent studies examining this relationship, then discuss the psychological meaning of the findings.

The International Association for the Study of Pain (1979) describes pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (Merskey, 1979). It may be described as either acute or chronic, depending on the time course; the latter is the focus of this review.

Impact.

Chronic or persistent pain can affect people across the lifespan, with significant impact on those who experience it. It is often associated with psychological distress and disability, and with economic and social disadvantage (Dohrenwend et al 1999; Elliot, Smith, Smith & Chambers, 1999). In one study 26% of chronic pain sufferers reported that pain had negatively affected their employment and a further 19% had lost their jobs as a direct result of their pain (Breivik, Collett, Ventafridda, Cohen & Gallacher, 2006). It is estimated that in the UK, 49% of individuals with chronic pain are also depressed (Donaldson, 2009).

The economic cost to society is considerable. An estimated 40% of GP visits are related to pain (Mantyselka, 2001), and in 1998 the cost to the UK of back pain alone was £12.3 billion. The Chief Medical Officer’s (CMO) Report states that this was mainly due to loss of work days (Donaldson, 2009) , but research in Australia argues that lost productivity at work is less a problem of absence than of reduced work effectiveness (Blyth, 2003; Leeuwen, Blyth, March, Nicholas & Cousins, 2006).

Prevalence.

According to the CMO's Report (Donaldson, 2009), approximately 7.8 million people in the United Kingdom have chronic pain, with a low recovery rate. Musculoskeletal disorders are the most common causes of chronic pain, with back pain the most widespread type (Sternberg, 1986). In the UK, back pain and osteoarthritis account for more than half of all chronic pain (Donaldson, 2009).

The prevalence of chronic pain in the community is difficult to estimate: one review reported a median prevalence rate of 15%, but estimates range from 2-40% (Verhaak, Kerssens, Dekker, Sorbi and Bensing, 1998).

Definition and measurement.

The International Association for the Study of Pain defines chronic pain as pain lasting three months or longer, on the assumption that tissue damage heals in this time. The pain literature, however, uses a range of cut-off points including 1 month (Magni, Carldieron, Rigatti-Lunchini & Merskey, 1990), 6 months (Potter & Jones, 1992), and 12 months (Brekke, Hjortdahl & Kvien, 2002). Alternative approaches include reference to the extent of disability (Koster, Bosma, Kempen, van Lenthe, Eijk & Mackenbach 2004).

Factors affecting onset and outcome.

The biopsychosocial model describes interacting factors impacting on the onset, experience and outcome of chronic pain. Female sex (Barsky, Peekna and Borus, 2001) and being middle aged or older (Gallagher, Verma, Mossey, 2000) increase the likelihood of reporting of pain, while certain health behaviours such as smoking (Palmer, Syddall, Cooper and Coggon, 2003) are also associated with higher prevalence. The risk factors for chronic pain are similar to those for many chronic health conditions (Mackenbach, Borsboom, Nusselder, Looman & Schrijvers, 2001).

Psychosocial factors include emotional states, particularly anxiety and depression (Macfarlane, Morris, Hunt, Benjamin and McBeth, 1999), past pain experience and health beliefs; those in turn influence pain-related behaviour and experience (Turk & Monarch, 2002; Newton-John, 2002).

A range of social and environmental factors such as reduced contact with social networks, and certain occupational aspects, such as heavy workload or repetitive movements (Harkness et al., 2003, Van der Windt et al., 2000), are associated with increased pain. Furthermore, behavioural expression of pain, such as grimacing, may evoke a range of reactions from others from support to indifference; these responses shape and modify the individual's pain-related behaviours (Morley, 2008). However, the social environment is arguably the least explored aspect of the biopsychosocial model (Blyth, 2008).

Socioeconomic factors.

This report will focus on one particular aspect of the social environment, socioeconomic status (SES). SES incorporates two dimensions along which individuals or communities of people can be ranked: economic (financial and material wealth) and social (aspects such as education and community standing).

Furthermore, the CMO's Report (Donaldson, 2009) states that those who are socially or financially disadvantaged are more likely to report chronic pain. Consistent with this, socioeconomic factors such as lower levels of education (Roth, Punch and Bachman, 2001), low income, and being unemployed (Portenoy, Ugarte, Fuller and Haas, 2004), have been found to be associated with higher rates of chronic and disabling pain.

The specific aspects of SES most closely associated with chronic pain, and the nature of the relationship, are unclear. Many studies reduce the complex phenomenon

of SES to just one or two factors, and fail to address the relationship with chronic pain.

Relevant review papers.

Two review papers describe the existing research on chronic pain and some initial findings on the SES – chronic pain relationship. Verhaak et al. (1998) reviewed 15 epidemiological studies on the prevalence of chronic pain in adults, finding rates from 2-40% and concluded that neither methodology nor measurement differences could account for the variation.

McBeth and Jones (2007) provide a broad overview of the research on three common types of musculoskeletal pains in both adults and adolescents: shoulder pain, low back pain and chronic widespread pain. They state that the prevalence of chronic pain varies according to group factors such as SES and race, and individual factors, such as smoking and psychological status; they recommend further research to clarify the nature of the associations.

Aims of this review.

This paper will review the literature examining the association between SES and the development, persistence and consequences of chronic pain, addressing the following questions:

1. Does the evidence support an association between chronic pain and SES?
2. What factors mediate any association between chronic pain and SES?
3. How does SES impact on people's ability to live with chronic pain?
4. What is the psychological meaning of the findings?

Review Methods

Initial scoping exercises uncovered two review papers examining the prevalence of chronic pain: Verhaak et al. (1998) and McBeth and Jones (2007). Brief summaries of these are provided above. McBeth and Jones (2007) summarise a very wide range of chronic pain literature; no individual study is reviewed in any depth. By contrast, the review by Verhaak et al. (1998) describe the 15 studies in detail. Their summary of studies before that date is sufficient to exclude them from this review.

Selected databases (PsycINFO, MEDLINE and Embase) and the reference lists of relevant papers were searched. Initial exploration developed the search term (*chronic adj3 pain*) or (*persistent pain*). Papers examining socioeconomic status were identified by exploding the search term *socioeconomic status* to include *exp family socioeconomic level/ or exp income level/ or exp lower class/ or exp social class/ or economic security/ or poverty*. These were combined. The searches were limited to studies of adults from 1998-2010. A total of 143 studies were identified.

Table 1
Search results

Database	Number of studies
PsycINFO	14
Medline	42
Embase	87
Total	143

Titles were scrutinised against inclusion and exclusion criteria. The inclusion criteria were that both SES and chronic pain were examined and that the focus was on

adults. A number of exclusion criteria were developed and these are detailed in Table 2. They were applied in the order presented in the table.

Table 2
Reasons for Excluding Studies
Exclusion criteria

Exclusion criteria	Number of studies excluded			
	PsycINFO	Medline	Embase	Total
Focussed on treatment outcome	4	7	28	39
SES not measured comprehensively or SES-chronic pain relationship not explored	4	25	46	75
Focussed on cancer/heart disease	0	1	2	3
Focussed on return to work	2	0	2	4
Not primarily adult	0	2	3	5
Development of measures	0	1	0	1
Not northern European	1	0	4	5
Extensions of 1958 cohort study	1	1	2	4
<i>Total excluded</i>	<i>12</i>	<i>37</i>	<i>87</i>	<i>136</i>
<i>INCLUDED</i>	<i>2</i>	<i>5</i>	<i>0</i>	<i>7</i>

As detailed in Table 2, the main reason for excluding studies was either inadequate measurement of SES or its relationship to chronic pain was not examined. For example, several studies explored the economic *consequences* of chronic pain. The restriction to northern European countries was made because of important differences between northern Europe and countries such as north America in how healthcare is provided and funded, in benefit systems, and in injury compensation. The reference lists of selected and unselected papers revealed a further 6 studies missed because pain was described as musculoskeletal pain, disabling pain, hip pain

and back pain. Re-running the original searches with the addition of these terms did not identify any further relevant studies.

Results

Overview of the methodologies employed

There was limited variation in study methodologies. Sample recruitment and data collection are shown in Table 3, below.

Table 3
Comparison of Methodologies

Author	Recruitment method	Data collection method	Sample	Sample size
Bergman et al. 2001	Postal survey	Self report questionnaire	Random sample from 2 municipalities in southwest Sweden Age: 20-74	2,425
Brekke et al. 2002	Postal survey (part of 1994 study by Department of Rheumatology)	Self report questionnaire	Randomly selected individuals in Oslo, Norway Age: 20-79	1,762
Christensen et al. 2006	Postal survey (part of Danish Longitudinal Study on Work, Unemployment and Health)	Self report questionnaire	Individuals in 10% Danish random national sample Age: 40-50	7,125
Davies et al. 2009	Postal survey	Self report questionnaire	Patients of 3 GP practices in NW England Age 18-50	2,782
Elliot et al. 1999	Postal survey	Self report questionnaire	Random sample of patients from 25 GP practices in Scotland Age: 25 +	3,605
Eachus et al. 1999	Postal survey	Interviewer and self report questionnaires	Random sample of patients from 40 GP practices in SW England Age 35+	954
Hagen et al. 2006	researchers trawled health records	Pre-existing data from self report questionnaires, health screens & stored data	All employed adults in a Norwegian county Age: 25 – 59	38,426
Jordan et al. 2008	Postal survey (part of NorStop)	Self report questionnaire	All patients over 50 years at 6 GP practices in Staffordshire, England Age: 50+	3,644
Koster et al. 2004	Postal survey (part of GLOBE study)	Self report questionnaire	Participants of the GLOBE study Age: 15-74 Y	1,384

Macfarlane et al. 2009	Postal survey (part of 1958 cohort study)	Self report questionnaire and nurse administered measures	Participants of the 1958 cohort study Age 45 Y (born in 1958)	7,927
Saastamoinen et al. 2005	Postal survey (part of Helsinki Health Study)	Self report questionnaire	Council employees in Helsinki, Finland. Ages: 40, 45, 50, 55 and 60	8,970
Smith et al. 2004	Postal survey (part of RGCP study)	Self report questionnaire	Women from 1968 oral contraception study Age: 42-81	10,073
Urwin et al. 1998	Postal survey (first phase of larger needs assessment study)	Self report questionnaire	Stratified sample of patients at 3 GP practices in Tameside and Glossop, England Age: 16+	2,250

Summary of findings

1. Does the evidence support an association between chronic pain and SES?

Cross sectional studies examining the association between CP and SES

Since the publication of Verhaak's review (1998), six studies have comprehensively examined the association between SES and chronic pain. These are described in Table 5, below.

Measurement of pain

The length of time used to define chronic pain in these studies varies. At the lower end, one week (Urwin et al., 1998) falls well short of most definitions but this study also measured pain-related disability. Eachus, Chan, Pearson, Proper & Davey Smith (1999) do not explicitly assess chronicity but it made an original contribution on severity. Measurement techniques varied from a simple question to an established self report instrument such as the Chronic Pain Grade questionnaire (CPG) (Saastamoinen, Leino-Arjas, Laaksonen & Lahelma, 2005). Similarly, questions on prevalence include point prevalence (Elliot, Smith, Penny, Smith & Chambers, 1999 and Saastamoinen et al. 2005), pain in the last month (Smith, Elliot and Hannaford, 2004) or last 12 months (Bergman, Herrstrom, Hogstrom, Petersson, Svensson & Jacobsson, 2001).

Table 4

Studies on the Association Between Chronic Pain and SES

Author	Pain measures	SES measures	Aims	Relevant findings
Bergman et al. 2001	Pain for at least 3 of last 12 months Site of pain	Education Occupational class Immigration status	To assess prevalence of chronic pain and its relationship to sociodemographic factors.	Sociodemographic factors including SES were more strongly associated with chronic widespread pain than chronic regional pain.
Elliot et al. 1999	Pain for 3 months + Screening questions on point prevalence and duration. Chronic Pain Grade Questionnaire	Housing tenure Employment type Education	To describe the prevalence of chronic pain according to sociodemographic factors.	Housing tenure and employment status were significantly associated with chronic pain.
Eachus et al. 1999	Chronicity implicit in severity measure Severity score	Townsend Index Occupation Education Car ownership Household income	To investigate the association between severity of hip pain, disability, and socioeconomic position.	People with lower SES experience more severe hip pain and have more comorbidity.
Saastamo inen et al. 2005	Pain for 3 months + Screening questions on point prevalence and duration. Chronic Pain Grade Questionnaire	Occupational class Household income Housing tenure Education	To identify the prevalence of SES factors associated with acute, chronic and chronic disabling pain in middle age employees.	Lower levels of education and lower occupational class is associated with chronic and disabling pain. For women educational level was the strongest predictor, for men it was occupational class.
Smith et al. 2004	Pain 3 months + Site of pain	Husband's occupation (measured in 1968).	To identify differences in the types of chronic pain, to determine whether chronic pain is a distinct diagnosis.	Manual social class and area of residence are related to all types of chronic pain.
Urwin et al. 1998	Pain in the past month lasting for more than a week, in a limited list of sites. MHQ to identify disability	Carstairs Index Employment status Housing	To compare the prevalence of pain in a variety of sites, and to explore the relation between pain, social deprivation and other variables.	People who live in socially deprived areas have more musculoskeletal symptoms, especially back pain

Measurement of SES.

As shown in Table 4, measures of SES varied from husband's occupation to housing tenure, occupational class, employment status and household income.

Two studies (Urwin et al., 1998; Eachus et al., 1999) also employed area level measures which derive deprivation categories from postcodes using national census data on factors such as occupational class, car ownership, and overcrowding.

Summary of findings.

The studies provide a mixed picture of the association between SES and chronic pain, with inconsistencies in relation to housing tenure (Elliot vs Saastamoinen) but more consistency on markers of occupational class and income (Bergman et al., 2001; Elliot et al., 1999; Saastamoinen et al., 2005). Smith et al. (2004) conclude that manual occupational class was independently associated with chronic pain, but the use of a single marker of SES, and one which was historical, means these findings should be interpreted cautiously. Disability, rather than experience of chronic pain, was associated with social disadvantage only in middle age (Urwin et al., 1998), and with deprivation (Eachus et al., 1999).

Each of the studies provides some support for the hypothesis that chronic pain is associated with SES, but the exact nature of the relationship is unclear. SES was more strongly associated with chronic pain for men than for women, and for women education also played a part. The variety of socioeconomic markers measured and the mixture of individual and area level factors used by

the studies makes drawing conclusions on the most relevant aspects of SES, or most useful markers of SES, difficult.

Blyth (2008) refers to a debate within epidemiological circles about whether individual or area level factors have the larger impact on health, highlighting that both can be targets for intervention. It should also be noted that non-response to postal questionnaires may have introduced possible bias, under-representing very disabled people, those with low literacy or without the language in which the data were collected. Moreover, each of the studies used data captured at a single point and so cannot elucidate the direction of the associations, although Smith et al. (2004) did find that for women, husband's occupational class in 1968 was associated with pain 35 years later.

Overall these studies show that not only are individuals of lower SES more likely to have chronic pain, but they are also more likely to have more severe, disabling pain and more comorbid chronic health conditions.

What factors mediate any association between chronic pain and SES and what is the psychological meaning of these findings?

Cross-sectional studies examining the factors mediating the SES – chronic pain relationship

Two cross sectional studies which attempt to determine factors which might mediate or explain associations between SES and chronic pain were identified in the current search.

Table 5.

Cross Sectional Studies Examining the Factors Mediating the Chronic Pain – SES Association

Authors	Pain measures	SES measures	Aims	Main findings
Hagen et al.	ICD-9 classification for various back pains	Occupational class Working conditions	To examine the extent to which occupational class, working conditions and individual lifestyle factors mediate the effect of formal education on disability pension due to back pain.	There is a strong and unexplained effect of education on claiming disability pension for back pain, which is not mediated by occupational class, working conditions or individual lifestyle.
Macfarlane et al.	Pain for 1 day last month Pain of more than 3 months duration Identification of area of pain	Occupational class Childhood SES based on father's job	To examine the extent to which pain varies by SES, whether childhood SES has a long term effect on pain, and whether any relationships are mediated by psychological ill health.	Pain increased with lower SES and childhood SES had an influence but is not as strong as adult SES. The pain SES relationship can only partly be explained by factors such as adverse life events and psychological distress as the relationship remained when these factors were adjusted for.

Measurement of pain

Macfarlane, Norrie, Atherton, Power & Jones (2009) measured chronic regional and chronic widespread pain (CWP) enabling comparisons between the two. Hagen, Tambs & Bjerkedal (2006) employed the somewhat unusual methodology of trawling employee health records to identify council employees that had both a diagnosis of an ICD-9 back disease and were in receipt of disability pension. This means that participants had permanent occupational disability status and therefore at the extreme end of the disabling pain spectrum.

Measurement of SES.

Macfarlane et al. (2009) recorded participants' occupations and applied the Registrar General's Social Class system to categorise individuals into 1 of 6

occupational groups. They also collected data on education, but chose not to use this data in the analysis. Hagen et al. (2006) focused on educational attainment.

Measurement of mediating factors.

Both studies attempted to identify mediating factors which may explain SES-chronic pain associations: Psychological distress, depression, anxiety and lifestyle factors (Macfarlane et al., 2009); and lifestyle factors plus physical and psychological demands of work (Hagen et al., 2006).

Main findings.

Macfarlane et al. (2009) found that low social class in adulthood was related to all types of chronic regional pains and to CWP. Lower childhood SES was also related to adult chronic pain, although not as strongly. Hagen et al. (2006) found that each year of formal education was associated with a decreased risk for disabling back pain. Lower occupational class was also a risk factor for disabling back pain.

Macfarlane et al. (2009) found that adult mental health, as measured by the revised Clinical Interview Schedule (rCIS) was associated with most regional pains and with chronic widespread pain. Recent life events were related to some but not all regional pains. They conclude that their findings on the association between SES and pain were partly mediated by adult mental health, psychological distress, adverse life events and lifestyle factors.

Hagen et al. (2006) discovered that all the lifestyle factors measured (smoking, body mass index, physical exercise, and alcohol consumption), and four of the five factors related to working conditions (e.g 'physically demanding work' and 'authority to plan your own work'), were significantly associated with disabling back pain. Despite this, regression analysis showed that less than

50% of the educational inequalities in back pain disability could be explained by occupational class and factors related to working conditions and lifestyle.

Discussion of findings.

The unique contribution of these papers is that they seek to go beyond simply quantifying the association between SES and chronic pain: they both attempt to identify factors that might at least in part explain the relationship and provide some psychological meaning for it. Given that SES is a difficult phenomenon to modify, an understanding of mediating factors, which may be more suitable targets for intervention, is a clinically useful route to take.

They both indicate that while a proportion of the relationship between SES and chronic pain can be explained by lifestyle and psychological factors, these cannot fully explain the association. The Hagen et al. (2006) paper demonstrates that even a combination of lifestyle, work conditions, and occupational class cannot fully explain the strong relationship between education and disabling back pain. Hagen et al. (2006) discuss some research findings which suggest that education may have an effect on adult pain and disability, not merely because it determines occupational class, which in turn mediates exposure to physically demanding jobs, but because well educated people are more likely to lead healthier lifestyles, avoiding risk behaviours such as smoking and obesity which have been shown to be related to pain (see Leboeuf-Yde, 1999, for a review).

It is of note however that Macfarlane et al. (2009) only used one measure of SES in their analysis. Evidence has emphasised that studies must use more than one measure of SES in order to fully understand the determinants of inequalities in health (Davey Smith et al., 1998). It has also been demonstrated

in the studies reviewed above that different markers of SES have produced different levels of association with chronic pain across the different studies. Furthermore, 367 participants who could not be assigned an occupational class category were excluded from the study (a further 1084 did not complete all of the questionnaires and were also excluded, leaving a total 7,927 participants). Whilst this is not a large proportion, it is likely to include those at the most severe end of the pain spectrum: those who are excluded from work due to their levels of pain interference. However, they do measure occupational class at two time points, birth and date of study, which enables the authors to compare the effects of each on adult chronic pain. It is the only paper in this review to do so.

Overall, while these two studies provide valuable contributions to our understanding of SES – chronic pain relationships, a lack of research in this area means that we still understand little of why individuals with lower SES report higher rates of chronic pain.

Prospective studies examining the nature of the relationship between SES and the onset of chronic pain

The studies in this section, see Table 6 below, employed a prospective design in order to identify who developed new pain and the factors associated with this.

Measurement of chronic pain

Pain of at least three months' duration was classified as chronic widespread pain (CWP) or not by Davies et al. (2009). Pain in the last four weeks was classified as disabling or not by Jordan, Thomas, Peat, Wilkie & Croft (2008) with the question "During the past four weeks, how much did pain

interfere with your normal work (including both work outside the home and housework)?”

Table 6
Prospective Studies Examining the Onset of Chronic Pain

Authors	Pain measures	SES measures	Aims	Main findings
Davies et al. 2009	Site of pain >1 day in past month, occurrence, chronicity (3 M+)	Area level based on Townsend Index. Individual level: Employment status	To examine whether SES predicts onset of CWP and if this can be explained by psychological factors.	10% of participants developed new CWP over 15 month period. Individuals with low SES are more likely to develop new pain, but this was no longer significant when psychological factors were controlled for.
Jordan et al. 2008	Pain 1 day in previous month. Pain interference question from Short Form-12	Area: Index of Multiple Deprivation Individual: Living arrangements Education Occupational status (last job) Perceived adequacy of income	To examine whether different cumulative exposures to social factors result in differing levels of disabling pain.	Characteristics of the pain and psychological factors are the main influences on disabling pain. Perceived adequacy of income is a significant predictor of new pain as is local deprivation status.

Measurement of SES.

In Davies et al. (2009), SES was determined using area level indicators of affluence, based on the Townsend Index score. The Townsend Index determines deprivation using information on home ownership, car ownership, unemployment and overcrowding and on individual employment status.

Jordan et al. (2008) sought to comprehensively measure SES at the individual (education, occupational class, and perceived adequacy of income) and area levels, with the aim of comparing the contribution of each to the onset

of disabling pain. Perceived adequacy of income is an interesting variant on the usual measures of material deprivation.

At an area level they used the Index of Multiple Deprivation (IMD) which uses postcodes to rank each area in England from most to least deprived (total 32,482 ranks), then grouped into three levels. Although the area level deprivation status is therefore very similar to that of Davies et al. (2009), the IMD takes into account a broader range of variables than the Townsend Index: income, employment, health, education, housing and services, crime, living environment, and 'overall deprivation'. Furthermore, pain was analysed separately for each of these variables.

Measurement of mediating factors

Both Davies et al. (2009) and Jordan (2008) measured a range of psychological and behavioural factors in an attempt to investigate whether these might be the mechanism by which SES is related to chronic pain.

The baseline postal survey of Davies et al. (2009) collected information on mediating factors using a total of 5 inventories: the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983); General Health Questionnaire (GHQ) (Goldberg and Williams, 1988); Somatic Symptoms Checklist (SSC) (Othmer and DeSouza, 1985); Illness Attitudes Scale (IAS) (Kellner, 1987); and the Threatening Life Events Inventory (Brugha et al., 1985).

Similarly, Jordan et al. (2008) employed the HADS. However, as a result of finding that 74% of the sample were either both anxious and depressed or neither anxious nor depressed, they collapsed the two disorders into one

category of psychological distress. Jordan et al. (2008) also measured contact with social networks and a number of other lifestyle factors.

Summary of Main Findings

Davies et al. (2009) found that 10% of participants who were CWP-free at baseline developed CWP over the course of 15 months. After controlling for age and gender, there was a significant inverse association between the SES of area of residence and the onset of new CWP. However, stepwise logistical regression showed that once individual baseline psychological factors were adjusted for, this relationship was no longer significant. They then added employment status and baseline pain status to the model, but it remained non-significant.

Participants in the two areas with lower SES were significantly more likely to have higher levels of psychological distress, anxiety and depression, illness behaviours, somatic symptoms, sleep problems, and threatening life events than participants in the most affluent area. Furthermore, a number of the psychological variables, such as sleep disturbance, were significantly associated with the onset of new CWP.

Jordan et al. (2008) found that 19% of respondents developed pain interference over three years. A crucial difference compared to the Davies et al. (2009) study is that they examined both individual and area level markers of SES separately (the individual level marker of employment status recorded by Davies et al. (2009) was only used as part of the stepwise logistical regression model).

In terms of individual level factors, Jordan et al. (2008) found that only perceived adequacy of income and known social networks were independently

associated with new pain once all the individual factors had been adjusted for. Contrary, perhaps, to some of the findings reviewed above, some individual SES factors - including occupational class and educational level - were not associated with new pain. They suggest this could be partly due to the study focussing on older adults, for whom these factors may not hold as much relevance as for working age individuals. However, as previous studies would have predicted, several lifestyle factors and psychological distress were associated with the development of disabling pain, but this study was additionally able to show that individual SES was not as strong a predictor of new pain as lifestyle and psychological factors.

In terms of area level SES, Jordan et al. (2008) analysed each of the domains of their deprivation index separately for each of the three area deprivation categories using multi-level modelling techniques. This enabled them to examine more closely what aspects of living in a deprived community might be associated with interfering pain, and might predict the onset of new pain. They found that the proportion of people who had interfering pain at baseline increased as deprivation increased for all domains except housing/services, and living environment. Similarly, the proportion of people who were pain-free at baseline but developed new disabling pain over three years also increased as deprivation increased in all domains except for housing/services.

A particularly interesting aspect of this study is that they were able to examine whether the effects of living in a deprived area could be explained by the differing individual level characteristics of the people living in those areas. They found that the general health of a neighbourhood predicts an individual's

likelihood of developing new pain, regardless of their individual characteristics. They suggest that this may be due to shared causes of poor health such as poorer access to health services.

Jordan's findings may be contrasted to those of Davies et al. (2009) which asserted that variations in chronic pain were due to psychological distress. It emerged in this study that the association between area level deprivation and the onset of new pain was only significant for people who were not depressed or anxious at baseline.

Discussion of Findings.

The longitudinal design of these studies enabled them to demonstrate that a number of psychological and lifestyle factors as baseline predict the development of new chronic pain, and may explain a significant proportion of the association between SES and chronic pain. Jordan et al. (2008) also found that almost all aspects of living in a deprived area predict the onset of new disabling pain.

The inclusion of both individual and area level socioeconomic markers, in combination with a prospective design, enables Jordan et al. (2008) to develop new insights into the SES-pain relationship. Their findings also underline the value in taking care to define and measure a range of SES factors. Whereas previous studies have reduced SES to one or two factors, Jordan et al. (2008) have shown that perceived deprivation and characteristics of one's neighbourhood rather than individual levels of deprivation may be better predictors of who develops disabling pain. Furthermore, their use of disabling pain rather than chronic pain makes their findings of particular relevance to the development and planning of services.

An interesting discrepancy has arisen between the strength of the association with area level SES in the onset of chronic pain: Jordan et al. (2008) found a much more prominent role for this than Davies et al. (2009). Perhaps this can be explained by considering how they measured area level SES. The measure used by Davies et al. (2009) took a sum of individual level factors to categorise the areas into one of three groups. However, there will inevitably be individuals whose personal SES does not match that of the postcode they are living in. Conversely, Jordan et al. (2008) additionally accounted for factors common to all people living in that particular area, such as the stress of living in a neighbourhood of high crime. In this way it is relevant to all people living in that area, even if they are personally financially better or worse off than the average person in their area.

Notably, Jordan et al. (2008) found that the general health of an area can shape everyone's experience of pain, not just that of the most deprived people in that area. This shows that individual risk factors do not exist in a vacuum and will interact with environmental risk and protective factors. It also echoes the consistent finding in the health inequalities literature, that inequality affects the health of everyone in that society, not just the poorest (Wilkinson & Pickett, 2010).

How does SES impact on individual's ability to live with chronic pain?

Studies looking at the implications of SES on living with chronic pain

The following studies explore how SES might impact on how people live with and manage chronic pain.

Table 7

Studies Looking at the Implications of SES on Living with Chronic Pain

Authors	Pain measures	SES measures	Aims	Main findings
Brekke et al. 2002	Non inflammatory musculoskeletal pain Intensity, duration & localisation Disability (mHAQ)	Utilises known data on SES of diff areas. 3 poorest and 3 richest.	To investigate the association between pain and residential areas of differing SES.	Living in the more deprived area meant strong, widespread pain and physical disability, higher use of analgesics and less involvement in own health care.
Koster et al. 2004	Standardised Nordic questionnaires for the analysis of musculoskeletal symptoms. Nottingham health profile to measure mobility problems.	Education level Household income Occupational class	To examine the association between SES and mobility decline and to determine whether any relationship could be explained by disease severity and comorbidity in four different chronic disease groups.	People with low SES had an increased risk of mobility problems, more severe disease and more comorbidity. However, disease severity and comorbidity contributed minimally in explaining the SES – mobility decline association.
Christensen et al. 2006	Pain in joints or back that has prevented activity	Occupational class Educational level	To examine the association between SES and coping in individuals with chronic pain.	SES has an impact on coping style but the nature of this relationship is different for men and women.

Measurement of pain and disability

Brekke, Hjortdahl and Kvien (2002) focused on a limited number of pain sites and measured intensity, duration and disability. The latter was measured with the modified Health Assessment Questionnaire (mHAQ) (Pincus, Summey, Soraci, Wallston & Hummon, 1987). Koster et al. (2004) focused on disability caused by low back pain and Christensen, Schmidt, Orsted Hougaard, Kriegbaum & Evald Holstein (2006) measured disability caused by joint pain.

Measurement of SES.

Brekke et al. (2002) measure SES at area level. They use known SES rankings of districts within Oslo, which are based on data such as income levels, employment, and housing standards, to identify three high SES districts in the west and three low SES districts in the east of the city. A total of 18 variables are used in this ranking system, capturing a wide range of socioeconomic factors. They also gathered individual data on occupational class and years of education.

Koster et al. (2004) measured three individual level SES variables: level of education; income (adjusted for household size); and occupational class. Meanwhile, Christensen et al. (2006) only measured occupational class.

Measurement of other variables

Brekke et al. (2002) measured psychological distress using the short version of the Symptoms Checklist (SCL-5) (Tambs & Moum, 1993). Quality of life and satisfaction with healthcare were also assessed. Specific to the aims of this study, a number of questions were asked to determine whether participants had consulted medical professionals in the past year, what advice they received, and whether they had received a diagnosis. Data were collected on analgesic and sedative drug use in addition to a range of demographics.

Koster et al. (2004) were primarily concerned with making comparisons across diseases. Therefore, the only other variable they gather data on was comorbidity which was defined as the number of other diseases participants reported. They distinguish between 'severe' and 'less severe' conditions.

A key variable for Christensen et al. (2006) was coping strategies. They developed a coping questionnaire (descriptions are provided on test-retest

reliability and validity), sampling active problem solving and avoidant coping. They also collected data on a number of covariates: physical exposures at work, psychosocial stressors at work, age and cohabiting status.

Main findings.

Brekke et al. (2002) initially report on a number of between-area differences. Those in the wealthier area were older, better educated, more were married, more exercised, and fewer smoked than those in the poorer area. They then describe that while similar numbers in each area had consulted a GP in the previous year, a greater proportion of those in the wealthier area had visited a rheumatologist. A greater proportion of those in the poorer area had taken analgesics and reported a low level of involvement in their own health care, an association which remained even after adjustment for pain intensity, disability and mental distress.

Those in the wealthier area were older than those in the poorer area, so age was adjusted for in the regression analysis. The findings from this were that living in the poorer area was significantly associated with higher levels of disability and mental distress, stronger and more widespread pain and lower life satisfaction.

For Koster et al. (2004), only the findings in relation to low back pain will be discussed here. At baseline they found that individuals with lower SES had more mobility problems. Each of the three measures of SES were significantly associated with mobility problems: lower education levels, lower income levels and lower occupational status. There was, however, no significant

association between SES and pain severity and only a modest association between SES and number of severe comorbid diseases.

Using their longitudinal data, Koster et al. (2004) were able to demonstrate that over the course of six years, mobility decline was significantly associated with having lower income and lower occupational class, but not with education. These relationships remained significant after adjustment for baseline mobility, comorbidity and pain severity, in addition to sex, marital status and age. As might be expected, having more severe pain or a higher number of severe comorbid diseases was also significantly associated with greater decline in mobility.

Christensen et al. (2006) found that for social classes III-IV and V, women showed less frequent use of problem-solving coping, an association which was strengthened when the covariates were added to the logistical regression. However, there was no increase in the use of avoidant coping with lower SES. For men, being in social class V was significantly associated with higher use of avoidant coping, but there were no associations between any of the occupational class categories and problem-solving.

In terms of mediating factors, descriptive statistics showed that those in lower social classes had more physical stressors at work and less support from colleagues, but at the same time felt that they had fewer emotional demands made on them at work.

Discussion of findings.

The findings by Brekke et al. (2002) are consistent with those of Jordan et al. (2008), showing that living in an area of low SES is significantly associated with more severe pain and greater levels of disability, even when a

number of possible confounding variables are adjusted for. Their findings also start to provide insight into the ways in which people of differing SES attempt to manage and cope with pain. Importantly, by controlling for a range of possible confounding variables, they were able to show that these different behaviours persist even when the severity of pain and level of disability are taken into account. This suggests that SES might affect how people react to severe, disabling pain, but alternatively, it might indicate that the quality of healthcare provision is lower in poorer areas.

The findings of Koster et al. (2004) essentially indicate that people with lower SES are more likely to have mobility problems as a result of having back pain, not necessarily because they have more severe pain or a greater number of comorbid health problems, but because something about low SES leads them to become more disabled by their pain. Their mixed findings, in terms of which markers of SES were consistently associated with disability (there was no significant association with education), again highlight the importance of using more than one measure of SES.

Overall, Christensen et al. (2006) provide evidence of a modest association between less problem-solving coping and more avoidant coping and lower SES in individuals with severely disabling pain. The details of the association differ for men and women, and the associations are most prominent in the lowest occupational classes. The authors acknowledge in their discussion that their exclusive focus on individuals whose pain had ‘very much’ affected their ability to perform their daily activities may have resulted in an overrepresentation of avoidant coping styles, thus affecting the findings. They cite a study by Klapow et al. (1995) which found that patients with higher levels

of pain relied more on avoiding activities as opposed to utilising social support or problem-solving. Christensen et al. (2006) stated that they may therefore have missed individuals who used more problem-solving coping. Furthermore, Christensen et al. (2006) used only one measure of SES, and as discussed earlier in this review, evidence indicates that this may not be sufficient (Davey Smith et al., 1998).

Their findings point towards the possibility that ways of coping might be one mechanism by which people with lower SES suffer more as a result of having pain, for example by having more severe pain and higher levels of disability (Brekke et al., 2002; Koster et al. 2004). It is of interest that Brekke et al. (2002) found that people of lower SES were more likely to use analgesics to manage their pain, as this is one of the items on the tool which Christensen et al (2006) designed specifically to measure avoidant coping. The findings of both studies indicate that individuals with lower SES use less problem-solving, a way of coping which has been shown to be associated with poorer adjustment to chronic pain (Holmes & Stevenson, 1990). However, findings on self-reported coping strategies should be interpreted with caution as scores relate to the frequency of use of the strategy and its match to the problem is not measured.

Discussion

Summary of research findings

The research reviewed will be summarised and discussed in relation to the first three aims of the review.

1. Does the evidence support an association between chronic pain and SES?

All the studies reviewed provide some evidence for an association between chronic pain and SES. For example, chronic pain was found to be more prevalent in those with lower levels of education or lower occupational class; the rate of onset of new chronic pain was found to increase with greater deprivation, and low SES was not only related to higher prevalence of chronic pain, but also to increased severity.

Studies which conceptualised SES more broadly, for example by recording a number of different markers or by measuring both area and individual level SES, were additionally able to consider the particular aspects of SES that might relate to chronic pain. For example, Jordan et al. (2008) concluded that the general health of a neighbourhood is a better predictor of an individual's likelihood of developing new pain than their individual SES.

2. What factors mediate any association between chronic pain and SES?

The studies reviewed in this section indicate that the association between SES and chronic pain is not a direct one, but that a multiple psychosocial factors mediate the relationship. These include mental health, lifestyle factors, and work place conditions. However, the analysis of one of the studies in particular indicated the complexity of the role of mediating factors, finding that while

lifestyle and work conditions were significantly associated with pain, they explained less than half the educational inequalities in disabling back pain.

3. How does SES impact on individual's ability to live with chronic pain?

In addition to being more likely to develop chronic pain, individuals with lower SES are more likely to suffer greater levels of disability, mental distress and lower life satisfaction, even when a number of confounding variables are statistically controlled. Moreover, coping behaviours appear to vary with SES, with those lower down the hierarchy being more likely to use analgesics, have lower levels of involvement in their own healthcare and be less likely to use problem-solving coping. There was also some suggestion that the impact of SES on living with chronic pain might be more pronounced for women than men, but this requires further investigation. In this way SES appears to impact on how people react to and manage chronic pain, but it might also reflect poorer primary care practices in more deprived areas.

Overall, this review has found support for the hypothesis that there is a relationship between chronic pain and SES. However, while each of the studies reviewed produced some supporting evidence, they also revealed several occurrences of no association between chronic pain and various markers of SES. There were also inconsistencies across the studies, with some discrepancies in the relative weight of SES compared to psychological and lifestyle factors, and the importance of individual versus area level SES.

The lack of clarity as to the nature of the SES-chronic pain relationship might largely be explained by methodological variations in (1) the conceptualisation and measurement of SES and (2) the definition and

measurement of chronic pain. Furthermore, very little if any discussion was provided in the studies reviewed of what the associations might mean.

What is the psychological explanation of the findings?

In instances where the epidemiological literature has taken into account psychological factors, these have been conceptualised narrowly, often as anxiety and depression scores. On the other hand, there is a wealth of literature examining the role of psychological factors in chronic pain. This has shown that the way in which individuals conceptualise, make sense of and think about their pain is linked to ratings of pain intensity and levels of pain related disability (Newton-John, 2002).

Furthermore, there is a large literature on the role emotional regulation can play in pain control. In particular, negative emotional states have been shown to not only be associated with chronic pain, but to predict pain persistence (see Keefe, Lumley, Anderson, Lynch and Carson (2001) for a review of this area). For example, one study experimentally induced elated, neutral or depressed mood in a sample of 55 adults with chronic back pain, then tested whether this impacted on pain tolerance and ratings of pain. Depressed mood led to significantly lower tolerance levels and higher pain ratings, whereas elated mood was associated with significantly greater levels of tolerance and lower pain ratings (Tang et al., 2008).

Unfortunately, however, there is little overlap between the epidemiological studies of chronic pain and research on psychological aspects. Therefore, in order to consider the final aim of review, which is to understand the psychological meaning of the findings, the next section will refer to the

wider health inequality literature and the literature on the psychological aspects of chronic pain.

Health and inequality.

In many respects, the findings of this review are consistent with the wider literature on health and SES. For example, the Whitehall studies found that lower job status was associated with higher risks of heart disease, depression, and back pain, and that being higher up the socioeconomic hierarchy does not just add years to life, but adds to the quality of health enjoyed in later life (Bosma et al., 1997; Marmot et al., 1991).

In considering what the explanation for these consistent findings might be, it is of note that all the participants of the Whitehall studies were employed, so absolute poverty could not explain why lower occupational status was associated with poorer health. Consistently, the studies in this review were all conducted in developed countries with state-provided health and education services. Therefore the differences in chronic pain observed cannot be due simply to absolute poverty or an inability to afford healthcare.

Furthermore, the Whitehall research also found that only one third of the increased risk from heart disease observed in the lower status groups could be explained by lifestyle factors such as the propensity to be more overweight and to smoke more (Smith et al. 1990). This is in line with the findings of Hagen et al. (2006), who found that while lifestyle factors and working conditions were significantly associated with disabling back pain, less than 50% of the educational inequalities in back pain disability could be explained by occupational class and factors related to working conditions and lifestyle.

Overall it appears that it is not absolute levels of wealth which explain the relationship between SES and health, but where people stand in relation to others in society. Wilkinson and Pickett (2010) propose that social comparison might be an important mechanism by which inequality leads to poorer health. They refer to a meta-analysis which reviewed 208 studies on stress and found that tasks involving a social-evaluative threat produced consistently higher levels of anxiety and by far the largest changes in cortisol levels, compared to any other type of psychological stressor (Dickerson & Kemeny, 2004). Given that anxiety has been shown to predict poorer adjustment to chronic pain (Hadjistavropoulos, Asmundson, Kowalyk, 2004; McCracken & Eccleston, 2003), social comparison might be one of the ways in which relative socioeconomic position is associated with chronic pain.

Furthermore, Twenge (2000) reviewed two meta-analyses examining changes in society's levels of anxiety. They found a significant increase in anxiety levels between 1950-1990, providing evidence that wider socio-cultural environment can have a considerable impact on well being. Twenge (2000) also concluded that economic factors were not related to the increase in anxiety, but that social factors such as social connectedness and environmental threat were more strongly associated with the increase in anxiety. This is perhaps consistent with the study by Jordan et al. (2008), in which neighbourhood social characteristics, such as the threat of crime, were better predictors of new chronic pain than income level. Perhaps also, in the northern European countries in this review, economic factors are relevant in that wealth is the standard by which individuals compare themselves to others in society.

The consequences of social comparison.

The consequences of feeling socially inferior, living in a less socially cohesive neighbourhood with a more imminent sense of threat, and having had few educational opportunities and therefore poorer job opportunities, are likely to mediate the range of psychological factors which are known to increase the risk of chronic pain.

A study found that having a low grade of employment is strongly associated with holding a general sense of unfairness. Furthermore, it showed that holding a sense of unfairness is in turn associated with coronary heart disease, and poorer physical and mental health. As this was a longitudinal study it was able to demonstrate that unfairness predicted increased rates of coronary heart disease, even after baseline health functioning and a number of other factors had been controlled for (De Vogli, Ferrie, Chandola, Kivimaki & Marmot, 2007).

In order to explain their findings the authors hypothesise that low social status serves as a continuous source of unfairness because people lower down the social hierarchy are more likely to be disrespected or treated as inferior by others. In this way they emphasise the role of 'social' rather than 'economic' position and this is in line with the findings of Twenge (2000) discussed above. De Vogli et al. (2007) argue that threats to a person's sense of self worth, caused by unfairness, might influence health via both emotional and biological pathways.

The relationship between healthcare and coping.

This review revealed that individuals from lower SES are less likely to be involved in their own healthcare, more likely to use analgesics and less likely

to use problem-solving coping. Importantly, research has shown that the way in which individuals attempt to cope with chronic pain impacts on the experience of pain. For example, studies on coping have indicated that maladaptive strategies to control or avoid pain can increase the aversive experience of pain (Asmundson & Norton, 1999), whereas acceptance of pain and the belief that one has control over pain is associated with less pain, disability, depression and pain-related anxiety, higher daily uptime, and better work status (McCracken & Eccleston, 2003).

It has been proposed that the observed differences in pain management behaviours between those of differing SES might be related to education levels. For example, it has been stated that many of the effective ways of coping with pain, such as reinterpretation, require cognitive skills that might be enhanced by education (Roth & Geisser, 2002). Perhaps also individuals develop coping strategies in childhood that are adaptive to the social environment they live in. Those of lower SES have been shown, for example, to be more likely to use avoidant coping strategies (Palomar, 2008). This might be adaptive for some aspects of their life, but less helpful for managing the problem of chronic pain.

However it may be that SES differences in coping are a reflection of the quality of healthcare provision for those of lower SES. This might arguably be due to underinvestment in poorer areas, or it might partly be the consequence of interactions between healthcare professionals and individuals of lower SES.

There is evidence showing that doctors' clinical decision making is influenced by SES (Hajjaj, Salek, Basra, Finlay, 2010) and that patients from lower social classes receive a more directive, less participatory consulting style (Willems, Deveugele, Derese, Maeseneer, 2005). Perhaps therefore, higher SES

individuals are able to have interactions with doctors in which they are able to participate and feel understood which may in turn promote acceptance of chronic pain and adherence to treatment plans and therefore reduce the likelihood of becoming caught in a loop of attempting to solve an unsolvable pain problem (Eccleston & Crombez, 2007). In pain, understanding what is wrong and what is not wrong or at risk underpins a self-management approach which incorporates more active strategies, including return to work and other normal activities (Newton-John, 2002).

Furthermore, Jordan et al. (2008) showed that there was something about living in a community with low SES that was more powerful than individual SES in predicting the onset of chronic pain. In particular, their study indicated that shared factors such as living in a high crime area were powerful determinants, irrespective of personal markers of SES. Evidence consistently shows that living in areas with high levels of crime, high rates of alcohol and drug misuse, and where buildings are run down, leads to anxiety and fear. Prolonged exposure to such anxieties can then lead to demoralisation and feelings of hopelessness (e.g. Steptoe & Feldman, 2001).

A recent study explored whether psychophysiological stress might be one of the mechanisms by which deprivation is related to poor health (Hill, Ross and Angel, 2005). They used self report to measure depression, fearful anxiety, a range of physiological stress responses such as dizziness and trouble breathing, and general health. The health measure used was broad and is likely to have captured a range of acute and chronic problems, including pain. They found that individuals who reported disorder in their neighbourhoods experienced higher rates of depression, fearful anxiety and autonomic arousal,

and poorer levels of physical health. Furthermore, they found that individuals who had lived in deprived neighbourhoods for longer had worse levels of health problems than those who had been in the same areas for shorter periods of time. They concluded that exposure to chronic, long term sources of stress has a more detrimental impact on health than intermittent stressors (Hill, Ross and Angel, 2005).

A role for absolute levels of deprivation?

Whilst the health inequality literature strongly points towards the importance of relative rather than absolute SES, there may still be elements of protection which the wealthy might be more able to purchase. For example, those with more money are more likely to be able to afford access to a chiropractor or physiotherapist, possibly supporting them in taking more control over their pain and reducing avoidance of activity. More wealthy individuals tend to have the financial capacity to work shorter hours and white collar jobs usually have better conditions of sick leave and facilities for those with disabilities to continue at work. Furthermore, professional and managerial jobs are less likely to place physical demands on individuals with pain problems, or have at least more opportunities for adaptation, than manual and unskilled jobs.

Individuals with chronic pain who are unable to remain in work (which is more common with lower SES) may consequently view themselves as more disabled and might be at greater risk of poorer mental health (Breslin & Mustard, 2003). This might in turn lead to more passive coping styles and erode confidence in their ability to cope with their pain. Consistently, it has been suggested that the social and economic consequences of longstanding illnesses

might aggravate further development of the illness (Lindholm, Burstrom & Diderichsen, 2002).

Implications for intervention.

Overall, the findings of this review suggest that opportunities for the prevention and treatment of chronic pain exist at both the individual and population level. Consistently, Blyth (2007) argues that intervening only with high risk individuals could prevent the possibility of reducing the overall burden of chronic pain on communities. Furthermore, in order to minimise those of lower SES continuing to suffer disproportionately from the consequences of chronic pain, it may be necessary to direct more resources that protect individuals from the social and economic consequences of chronic pain.

Limitations.

A limitation of the review is that it includes only minimal critique of the studies included. The review could be strengthened by receiving input from an individual more experienced in epidemiology, enabling more detailed consideration of the methodological strengths and weakness of each paper and greater discussion about the conclusions which could be drawn from each.

Conclusion

Those at the lower end of the SES spectrum are not only more likely to develop chronic pain, but will suffer more adverse consequences as a result of their pain. This relationship is not a direct one, however, and a wide range of psychosocial factors mediates both the experience of pain and the consequences of SES. One of the processes impacting on the association between chronic pain and SES is likely to be that of social comparison, which is associated with a number of cognitive and emotional processes such as heightened levels of

anxiety which may in turn exacerbate the persistence of chronic pain. Less satisfactory interactions between patients of lower SES and healthcare professionals may also affect how patients understand their pain and therefore what they consider sensible or risky to do; this in turn affects their experience of pain. However, more research is needed which explores the psychological processes which result from inequality and which mediate the onset, persistence and consequences of chronic pain. More thought and exploration is also required into how chronic pain can be better prevented at both an individual and societal level.

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PART 2: EMPIRICAL PAPER

How do Patients Understand Chronic Orofacial Pain?

Abstract

Models such as the biopsychosocial model have led to progressive advances in healthcare professionals' understanding of chronic pain. However, the ways in which patients themselves understand their pain is under-researched, particularly in orofacial pain which involves the face and mouth. This qualitative study samples patients with chronic orofacial pain to explore their understanding of their pain and their beliefs and fears about the causes and maintenance of their pain, both before and after an initial consultation at a specialist pain clinic.

12 participants were interviewed and completed a letter writing task and self report measures. Thematic analysis was employed to describe and analyse the data resulting in four themes: lack of information exacerbates helplessness; worry as part of the process of making sense of the pain; validation of the pain experience; and the importance of trust.

The themes describe the development of patients' fears and beliefs through processes of worrying and seeking validation of the pain experience. The data showed a lack of information can exacerbate hopelessness and worry but educating patients on their chronic pain condition can only achieve its aims when delivered clearly and sensitively, and when patients trust their doctor. When these conditions are met patients can make changes to the way they make sense of and manage their pain, and the degree to which it interferes with their life. The clinical and research implications of the findings are also discussed.

Introduction

This introduction will provide a brief overview of the main theories of chronic pain with particular focus on the role of cognitive factors. Chronic orofacial pain will then be described followed by a discussion of the different factors that might shape orofacial pain patients' understanding of their pain. It will be argued that gaining a fuller understanding of how patients with chronic orofacial pain conceptualise their pain will be of significant clinical utility.

Pain.

The International Association for the Study of Pain (1979) describes pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”. It may be described as either acute or chronic, the latter having lasted for more than three months and not associated with ongoing damage or disease (Merskey, 1994). An important implication of this definition is that pain cannot be disconfirmed by the absence of physical findings.

Chronic or persistent pain is often associated with significant levels of distress and disability and high usage of healthcare services (Breivik, 2006). Depression in particular is more prevalent in individuals with chronic pain than in the general population or other patient groups, (e.g. Tunks, Crook & Weir 2008) and it is not uncommon for chronic pain patients to have comorbid health conditions such as IBS (Kato et al., 2006) due to the process of central sensitisation (e.g. Freeman, Nystrom, & Centeno, 2009).

Chronic pain theories.

Over the years several theories have been proposed to explain the experience of chronic pain. Dualistic understandings of pain recognise pain as a symptom for which a cause, often structural, is sought. In acute pain there may be a treatable cause but chronic pain frequently exists without objectively observable structural abnormalities in the body. Traditionally the concept of somatisation was employed to explain this, suggesting that pain is the result of underlying emotional conflict the patient is unable to face (Holloway & Zerbe, 2000). There is very little, if any, evidence to support this model and it is based on the controversial process of diagnosis by exclusion. Although emotional distress is often observed in chronic pain patients this is more often a consequence than a cause of pain (Dohrenwend et al., 1999).

A much broader and more comprehensive understanding of pain began to develop with the introduction of the gate control theory (Melzack & Wall, 1965). It was the first theory to postulate that variables such as mood, attention and past encounters with pain influence the experience of pain. This theory has led to the development of the biopsychosocial model which describes chronic pain as resulting from a dynamic interaction of biological, psychological and social factors. It emphasises people as ‘active processors’ of information whose expectations, beliefs and interpretations of events will influence their choice of coping strategy, the response they evoke from people around them, and ultimately their subjective experience of pain and disability (Turk & Monarch, 2002). The biopsychosocial model has led to assessment and treatment procedures which take into account some of these factors, with better outcomes

in terms of reduced pain and lower levels of depression (e.g. Gatchel et al, 2006).

The role of cognitions in chronic pain.

Since the development of the gate control theory a large body of literature examining the role of cognitive factors in chronic pain has emerged. We now know that the way in which patients construe their pain and the meaning they give to it determines their affective reaction to the pain, the health related behaviours they engage in and consequently their overall functioning (Newton-John, 2002). For example, beliefs about the causes of pain may influence adherence to treatment or whether further medical opinions are sought (Williams & Thorn, 1989). Beliefs about why pain persists or how it may continue in the future affect mood, particularly anxiety if the cause of pain is unknown, and views about the implications of using a painful part may lead patients to avoid using it, resulting in loss of previously valued activities and increasing disability (see Newton-John, 2002 for an overview).

Furthermore, it has been observed that some people with chronic pain manage to function well in everyday life, and that chronic pain is not necessarily synonymous with disability and depression. The literature describes a number of cognitive styles which are associated with more or less successful management of chronic pain. For example, greater acceptance of pain has been linked to better emotional, physical and social functioning and less healthcare use (McCracken & Eccleston, 2004; Viane et al., 2003, McCracken & Eccleston, 2005). Those who are less accepting may become focussed on trying to control or avoid pain, however unsuccessfully.

Consistent with the literature on acceptance, Eccleston, Crombez, and Aldrich (2001) proposed that the way in which patients ‘frame’ or understand their pain will have implications for the success of their search for a solution to their problem of pain. Patients who fear that pain intensity is proportional to tissue damage, and who hold beliefs that all pain can be cured, become trapped in a cycle of pursuing a cure when in fact none exists. On the other hand, individuals who frame the problem as how to live a more fulfilling life in spite of pain will be better placed to find ways to do this (Eccleston, et al., 2001).

Research has also shown that individuals who believe they have some control over their pain have better treatment outcomes, whereas those who adhere to ideas that they are disabled or that pain is a signal of damage are more likely to engage in unhelpful behaviours such as guarding and resting, which can lead to ‘acquired’ disability (Jensen, Turner and Romano, 2001). Additionally, catastrophic thinking is a particular cognitive style which has repeatedly been associated with higher levels of perceived pain, disability and emotional distress (e.g. Severeijns et al., 2001). Research indicates that this is not simply a correlation, but that catastrophic thinking can actually predict the presence and persistence of pain (Drahovzal, Stewart & Sullivan, 2006).

Taken together, the literature on the role of cognitions indicates that the beliefs and expectations patients hold can have a significant impact on both the subjective experience of chronic pain and on pain-related outcomes such as healthcare use and disability.

The role of lay beliefs.

Consistent with the literature on the role of cognitions in chronic pain is the research into lay health beliefs. It has shown that the “cognitive sets” which

patients hold about their condition determine their behaviours in relation to their health (Cooper, 1998) and although a comprehensive theoretical explanation of chronic pain now exists, this does not mean that lay people understand pain in this way. In fact, Feinman & Newton-John (2004) argue that despite enormous shifts in lay health beliefs in many areas, including smoking and heart disease, beliefs about chronic pain and its treatment have changed little for hundreds of years and most of the general public associate pain with tissue damage. Newton-John (2002) argues that a false dichotomy between the physiology and psychology of pain posited in the early theories of pain still exist in lay circles, suggesting that many chronic pain patients may also conceptualise pain in this dualistic manner. However chronic orofacial pain patients may also be subject to a number of unique experiences which will also shape their conceptualisation. Before describing what these are, an overview of orofacial pain is given below.

Orofacial pain.

Orofacial pain is a set of conditions involving the face and mouth. No clearly agreed diagnostic system exists to categorise this heterogeneous group of disorders although they are usually separated into neuropathic conditions (resulting from damage to the central or peripheral nervous system e.g. trigeminal neuralgia and burning mouth syndrome), muscular/joint pain (e.g. temporomandibular joint disorder), and atypical pain consisting of those which do not fit these categories.

An epidemiological study by Macfarlane (2002) found that in a sample largely representative of the UK general population 26% had some form of orofacial pain. It was most common in women and in the 18-25 year age

bracket, perhaps due to the preponderance of wisdom tooth pain at this age. Seventeen percent had taken time off work or were unable to carry out normal activities as a direct result of the pain. Further, an investigation of patients with temporomandibular joint disorder (TMD: Murray, Locker, Mock and Tenenbaum (1996) who had been referred to a specialist clinic and found that a half had difficulty eating and a third had sleep problems and depression. Zakrzewska (2009) states that of the facial causes of pain, TMDs are the most common. Overall, the epidemiological research on orofacial pain demonstrates that it is not an uncommon type of pain and that it can have significant impact on individuals' lives.

Despite this, facial pain conditions are often poorly understood and descriptions of disorders tend to be influenced by the background of the specialist assessing the patient (Madland & Feinman, 2001). Wessely et al (1999, p936) state that specialists tend "to focus on only those symptoms pertinent to their speciality, rather than any real differences between patients". Models such as the biopsychosocial may have led to advances in theoretical explanations of chronic orofacial pain but professionals from different specialities may differ in their familiarity with and interpretation of such models depending on their knowledge and experience. As such, it seems that different professionals may hold quite diverse explanatory models for the cause and maintenance of a particular chronic pain.

Madland and Feinman (2001) state that ear, nose and throat surgeons might hold an outdated theory originally posited by Costen (cited in Madland & Feinman, 2001) which holds that oral pain is due to missing molar teeth. The National Institute of Health now states that there is no evidence to support this,

yet invasive treatment continues to be provided by some practitioners, often causing more discomfort (National Institute of Health, 1996). Meanwhile, Dworkin (2008) purports that dentists are generally less likely to take a broader view of pain that encompasses psychosocial factors as their clinical expertise does not tend to involve the assessment of these factors and they are not trained in the use of measurement scales or interview schedules.

Zakrzewska (2009) explains that individuals have to decide whether to consult a general practitioner or dentist, and that the decision they make will dictate the treatment they receive. Furthermore, it seems that many patients perceive orofacial pain as a toothache-type pain and this will influence their decision of whom to consult. Zakrzewska (2009) also asserts that many patients whose pain is not dental in origin are nonetheless given dental treatments. When the pain is not resolved they might then consult a doctor, but Madland (2001) states that even when patients present to GPs, artificial distinctions in orofacial pain presentations may lead similar patients to be referred to varied specialists such as neurologists or maxillofacial surgeons, some of whom are not expert in pain. By the time orofacial pain patients reach a specialist pain clinic they will, perhaps more so than other pain patients, have seen several different types of health professional who will have classified and treated the pain quite differently (Zakrzewska, 2009).

Perhaps also the site of this type of pain has qualitatively different implications for patients than chronic pain elsewhere in the body. A qualitative study by Wolf (2008) revealed that orofacial pain patients described viewing their pain as in a class of its own compared to other types of chronic pain. Furthermore, Dworkin (2008) posits that because the face is key to critical

functions such as eating, breathing, swallowing and communicating, psychological factors may play a particularly important role when pain is experienced in this part of the body. Consistently, Zakrzewska (2002) explains that whilst the treatment of chronic orofacial pain is very similar to other chronic pains, she emphasises that the head and facial area may play a particularly prominent role in the development of self esteem and that pain in this area might have significant impact on interpersonal relationships or body image.

It seems likely that patients with chronic orofacial pain who reach a specialist pain clinic may have particularly diverse ways of conceptualising their pain, influenced by the explanations they have heard from various health professionals seen on their often complicated journey to the clinic, and by interactions with friends and family. The way in which patients with chronic orofacial pain understand their pain is, however, little researched.

Aims of this research

Developing a clearer account of how patients construct an understanding of their orofacial pain will be clinically useful. We now know that certain ways of thinking about pain are less conducive to effective management of chronic pain and can prevent people from pursuing satisfying and productive lives; it will be helpful to understand whether these types of cognitions are common in this patient group. Moreover, the nature of patients' understanding will have implications for how information given by clinicians about diagnosis or pain management is received. For example, cognitive theory describes a process called assimilation whereby new information is processed in a way that modifies it to fit with an individual's existing schemas, or categories of knowledge

(Piaget, 1952; Schallert, 1982). This suggests that individuals do not process information in a neutral way, rather that what is understood and retained will be shaped by the knowledge they already hold.

Fears and beliefs associated with chronic orofacial pain are so far unexplored, and there are always considerable differences between individuals in the subjective experience of chronic pain (Mitchell and MacDonald, 2009). Qualitative research methods, involving in-depth accounts from patients with chronic orofacial pain, have therefore been chosen in order to carry out a detailed examination of their beliefs and fears about the causes and maintenance of their pain. This study also examined whether patients' understanding of their pain changed following initial consultation at a specialist orofacial pain clinic. It will address the following questions:

- How do chronic orofacial pain patients understand their pain?
- What are their beliefs and fears about the causes and maintenance of their pain?
- How do their beliefs and fears change following the consultation?
- What are patients' experiences of the consultation, in terms of feeling understood?

Method

Design

A largely qualitative approach was employed, using a combination of semi-structured interviews and written narratives. It was intended that the use of written narratives would enable participants to reflect on their experiences in their own time, using a different medium supplementing the information gained at interview. Information was gathered both before and after each participant's

initial consultation in order to explore how her/his fears and beliefs changed following a consultation at a specialist pain clinic.

The pain clinic consultations are 45 minutes to one hour in length and involve history taking and the use of questionnaires and psychometric tests. A dental or facial examination is carried out but scans and x-rays are very rare. They often start with a review of the patients completed questionnaire on treatment goals and the opening question is “tell me what do you think I need to know?” The long appointment is designed to facilitate time for the patient to feel listened to by the doctor, a diagnosis to be made based on history and time for the diagnosis to be given, explained and a treatment plan formulated.

In order to keep the experience of each participant as similar as possible, it would have been preferable for each participant to have seen the same doctor, but this would have reduced the recruitable population to too small a size within the time available. Additionally, patients are sometimes reallocated to a different doctor on the day of the clinic. Therefore, patients due to see any of the doctors (ranging from consultant to specialist registrar) at the clinic were included in the study. Since all doctors are very closely supervised by the lead consultant and follow the same model for their consultations, there was less variability in the way in which the doctors conducted consultations than is usually the case.

Ethics

Ethical approval for the study was obtained from the Central London Research Ethics Committee 1 on 6th September 2010 (Appendix 1). The researcher was mindful that some patients could find talking about their pain difficult and an opportunity to meet either a clinical psychologist working in the

pain clinic or the lead consultant of the service was available for anyone who found the process distressing.

Selection of Participants

The study was carried out in a specialist orofacial pain clinic in London. Referral letters of patients on the waiting list for an initial consultation were scanned by the research supervisor, who works in the pain clinic, to identify patients who were aged 18 years or above, had chronic orofacial pain of non-dental origin, and were able to speak and read English fluently.

Individuals were excluded if they had previously been seen at the clinic, had a current diagnosis of cancer, or had a degenerative cognitive disorder such as dementia which could affect their ability to take part in the interview.

All those who appeared to be suitable for inclusion were sent a letter inviting them to participate in the study and an information sheet (Appendices 2 and 3). The letter encouraged those who would like to take part to contact the researcher to opt in and the researcher then telephoned them to discuss the study in more detail and check that they met the inclusion criteria. Those who were confirmed as meeting the inclusion criteria and who agreed to participate were invited for an interview.

Participants were informed in the initial invitation letter that participation was voluntary, that their decision to take part would not affect their care at the clinic in any way, and that they could withdraw at any stage. It was stressed that everything they shared at interview and in their letter would be anonymous and

not shared with their doctor. Informed consent to participate was obtained when the participant and researcher met for the initial interview.

Materials and measures

Semi-structured interview schedules were developed by the researcher for both the pre- and post- consultation interviews (Appendices 5 and 7), in addition to a form for collecting demographic details such as age and occupation (Appendix 4). An initial version of the pre-consultation schedule was piloted on one individual and minor changes to the structure and question content were made. A guidance sheet was also devised to support participants in writing the letter to the researcher following their consultation (Appendix 6).

Two self-report measures were also used pre- and post-consultation in order to gather information which, while not central to the study's aims, would serve as a useful supplement to and context for the qualitative information.

The Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983) is a 14 item self report measure which was developed to identify anxiety and depression in non-psychiatric hospital settings (Appendix 8). It contains an anxiety and a depression subscale, each containing seven items, without any of the somatic items such as insomnia common in anxiety and depression questionnaires. Numerous studies have been conducted on the HADS, testing it in a wide range of populations. In a review of 747 studies assessing the reliability and validity of the HADS (Bjelland, Dahl, Haug and Neckelmann (2002), alphas for internal reliability of the anxiety subscale ranged from 0.68 to 0.93 (mean 0.83), and from 0.67 to 0.90 (mean 0.82) for the depression subscale. Their review also found that HADS demonstrated similar

sensitivity and specificity to the General Health Questionnaire and a number of other short questionnaires for anxiety and depression such as the Beck Depression Inventory. The alphas ranged from 0.60 to 0.80. They concluded that the concurrent validity of HADS is good to very good.

The Brief Pain Inventory (BPI) (Cleeland, 1991) is a 15 item, self-administered questionnaire designed to assess the intensity and impact of pain (Appendix 9). It was originally designed for cancer patients but performs well in chronic non-cancer populations (Keller, et al., 2004). It consists of a pain severity scale and an interference scale. In 2004, Keller et al. examined the reliability and validity of the scale for arthritis and low back pain patients and found that the internal reliability of this scale ranged from 0.82 to 0.95. They also demonstrated the criterion validity of the measure by showing that it correlated highly with the SF-36 bodily pain scale, a widely used and well validated measure. Alphas ranged from 0.61 to 0.74, suggesting that they are measuring similar constructs. They also demonstrated the BPI to be sensitive to changes in disability for their sample group. They concluded that the BPI is suitable for measuring pain intensity and disability, that it presents a low burden for the respondent, is easy to use and interpret and is applicable across pains of varying aetiologies.

Procedure

There were three stages of dialogue between the researcher and the participants:

Part 1: Pre-consultation interview.

The pre-consultation interview took the form of a one-to-one meeting between the researcher and participant and was conducted in a clinical room in one of the trust's hospitals. The pain clinic had asked that this did not take place on the same day that patients met their doctor, so all interviews were carried out one to two weeks before participants' initial consultation. The researcher began by reminding the participant of the aims of the study and invited questions. Written consent was then obtained and a number of demographic details collected (Appendix 4). The researcher interviewed the participant about their fears and beliefs about their pain using the semi-structured interview schedule. This was audio-recorded and lasted 35-50 minutes. It covered the following areas:

- The participant's experience of pain.
- The participant's journey up to referral to the pain clinic; which professionals they had consulted, and how long they had her/his pain.
- The participant's understanding of what caused her/his pain and why they think it persists.
- The participant's expectations of and concerns about consultation at the pain clinic.
- Reflections on the interview process.

Part 2: Letter to the researcher.

At the end of the pre-consultation interview, participants were reminded about part two. The researcher asked the participant to write a letter to her, approximately one side of A4, following the consultation with the doctor. The

researcher advised participants that the letter should describe what they learned from the pain clinic and how they perceived the doctor's understanding of their problem. They were asked to try to complete this the day after their consultation. A guidance sheet (Appendix 6) was given to them to take home to support them in this task. If the researcher had not received a participant's letter within four to seven days of their consultation (depending on whether the participant was using e-mail or post) she sent a reminder. All participants responded to this prompt and the letters were received approximately one week after each participant's consultation.

Part 3: Post-consultation interview.

As the researcher received letters from participants, she contacted them to arrange an appointment for the post-consultation interview. This was carried out over the telephone. It had felt important to meet with participants face-to-face for the initial interview to facilitate rapport and the likelihood that participants would feel able to talk openly. However, it was reasonable to minimise travel for patients, especially as many lived far from the hospital. Furthermore, the aim of the post-consultation interview was to explore changes in patients' fears and beliefs following their consultation, and in every instance these interviews were much shorter than the pre-consultation interview, ranging from 8-15 minutes. This telephone interview was also audio-recorded and covered the following:

- Whether a diagnosis was given and the participant's thoughts about this.
- An exploration of any aspect of the participant's understanding of pain which had changed since the consultation.
- Where necessary, a follow-up of points raised in the letter to the researcher.

The audio recordings of both the pre- and post-consultation interviews were transcribed by the researcher. This took place during the same time period as the data collection which helped the researcher to refine her interviewing style.

Self-report data.

The HADS and short form of the BPI are routinely given to patients of the pain clinic prior to their initial consultation and participants were asked for permission to access theirs. Participants were also asked to repeat the HADS and BPI approximately one week after their consultation and return them to the researcher.

Data analysis

The transcriptions and letters from the participants were analysed using Thematic Analysis (TA). The aim of this analysis is to identify the meaning the participants give to the topic under investigation and to identify themes that are valid across participants (Joffe and Yardley, 2004).

TA was chosen because it would enable a rich description of the process of understanding that patients of chronic orofacial pain describe, and the impact the specialist pain clinic consultation might have on this, without the theoretical restrictions of grounded theory.

First the audio recordings were transcribed verbatim by the researcher and personal identifiers were removed. The researcher reflected on each transcript after typing it and underlined interesting phrases and made brief notes on the key ideas it contained.

Once all the transcripts had been collated it was apparent that they included lengthy descriptions of each participant's pain experience and their

attempts to manage it. Whilst not relevant to the aims of the study it provided important contextual information so this was summarised in table format.

The remaining data was coded for fears and beliefs about the causes and maintenance of the participant's pain (see Appendix 10). Each of the codes was entered into a coding table with a description and an example of text that the code had been applied to. As the process of coding took place the coding table was organised into categories. This helped facilitate coding, and served to organise the data, providing a platform from which to begin the analysis.

Once all the transcripts had been coded the categories were compared across each transcript so that similarities and differences could be identified and to ensure that the list was comprehensive enough to incorporate all data. Codes which occurred frequently were highlighted and note was also taken of codes which were different to the rest of the category or unique to a particular participant.

Next the coding categories were compared to one another. Categories that were similar were combined; those that were overly heterogeneous were split (see Appendix 11). Groups of categories which appeared to link to form sequences were entered into flow diagrams and this helped to identify the participants' processes of understanding. This enabled the identification of four themes.

During the analysis it was noted that there was variation in how individuals approached the written narrative. Several had not used it to reflect on changes in their understanding of their pain post-consultation, but had described the process of the appointment and things they were frustrated by or pleased with. It was not possible to identify whether any changes developed over the

period of one week between the narrative and follow up interview. Consequently, it was decided that the written narrative and post consultation interview data would be combined and analysed together, for all the participants.

Several examples of coded transcripts, the coding table and the themes were given to the external supervisor of the study, who is experienced in qualitative analysis and with orofacial pain, to check the validity of the themes. In particular they were examined to ensure that they provided an even representation of the data and that the level of interpretation had enabled new understandings to emerge without misrepresenting the original data.

The supervisor provided several comments which helped refine and enhance three of the themes, and these were incorporated. She felt that one of the themes included too many opposing ideas; this theme was dropped and a new theme was jointly developed. The supervisor felt that the final themes represented the data well and mirrored her extensive clinical experience with this population.

Results

As described in Table 1, 12 participants took part in the study: three men and nine women from 26-73 years of age.

Contextual data

Table 1
Demographic Details of Participants

	Age	Sex	Ethnicity	Occupational class	Marital status	Other chronic conditions
01	52	Male	White British	Skilled manual	Single	CFS
02	53	Male	White British	Skilled manual	Married	Mild leg pain
03	60	Female	White Greek-Armenian	Unemployed	Divorced	CFS & Fibromyalgia
04	41	Female	White British	Managerial/professional	Cohabiting	Back pain
05	43	Female	White other	Unemployed	Separated	None
06	34	Male	White other	Managerial/professional	Cohabiting	None
07	39	Female	Asian Indian	Student	Single	None
08	73	Female	White British	Retired	Married	Hyperthyroidism
09	43	Male	White British	Managerial/professional	Married	Gout
10	38	Female	White British	Skilled manual	Married	Bladder pain
11	50	Female	White Polish	Skilled manual	Cohabiting	None
12	26	Female	White British	Managerial/professional	Single	None
	mean = 46 SD = 12					

Table 2

Summary of Pain Experience

Key: ENT – Ear Nose Throat; TGN – Trigeminal Neuralgia; TMD – Temporomandibular joint disorder; TMJ – Temporomandibular joint;

	Onset of pain and length of pain at interview	Description of pain	Professionals seen	Prior pain clinic	Diagnosis at referral	Impact of pain	Previous attempts to relieve pain
01 M	Gradual build up of pain, for no apparent reason. 3 ½ years	Variable but unrelenting sensation of pressure behind nose and eyes. Also has headaches and hot flushes.	GP Neurologist ENT doctor	No	None	When the headaches get bad they are ‘unbearable’ and prevent sleep. Has had thoughts of ending his life.	Prescription medication Exercise Inversion table Sleeping/resting
02 F	Directly followed a trauma to the face 17 years ago. 17 years	Constant, intense pain in right cheek, like someone standing on his face, occasionally accompanied by ‘electric shock’ pains and toothache.	GP Maxillofacial Dentist Alternative practitioners	Yes	None	During ‘electric shock’ pains has to stop and rest. Terrified of face being touched. Difficulty sleeping and eating. Had teeth removed, unnecessarily.	Prescription medication 17 operations Alternative therapies
03 F	Has had pain since childhood which she attributes to a number of causes e.g. facial trauma. 41 years	Variable, sharp pain in eyes and ears. Numbness in face and headaches. Jaw feels locked and has difficulty swallowing. Toothache pains.	Dentist GP Alternative practitioners	No	Fibro- myalgia	Has had to change to a soft diet and when the pain is bad it interrupts her concentration. Describes feeling like she is ‘waiting for death’.	Prescription medication Alternative therapies Wisdom teeth removed
04 F	Pain started after breaking a tooth and has progressed to affect all of her teeth. 1 year	Variable in intensity, but always present aching and bruising pains in teeth and sometimes has ‘electric shock’ pains.	Dentist Neurologist Maxillofacial Psychotherap ist	Yes	None	Changed to a soft, warm diet so can’t eat socially. Her teeth are so sensitive that she cannot bear cold wind or air conditioning.	Prescription medication Psychotherapy Meditation
05 F	Pain since childhood following a trauma to the face. 30 years	Has an ache behind her eyes and cheeks and toothache. Has varied in intensity over time.	GP Dentists ENT doctor	No	None	Has not made major changes to her life but has had to live with pain for 30 years.	Wisdom teeth removed Gave up dairy Decongestants Paracetamol
06 M	Sudden onset of pain following a particularly bad bout of tonsillitis. 6 months	Pain in lower jaw which is always present but the part of the jaw which is most painful changes. Also has sensitive teeth.	GP	No	None	Initially it affected his work but has now found ways to prevent the pain interfering with his life as much. Worries about the cause of the pain.	Ibuprofen

07 F	Reasonably sudden onset of pain following an incident where it felt like she had broken a tooth. <i>2 years</i>	Initially the pain affected one side of her mouth, but then all her teeth became “excruciating”.	Dentist	No	Grinding teeth	Had to restrict her diet and has cut out e.g. fruit. Her restricted diet affects her ability to eat socially. Feels her teeth are “ruined”	Mouth guard Mouthwash.
08 F	Gradual onset of pain over many years which got worse 10 years ago for no identifiable reason. <i>10 years</i>	Tenderness across cheeks and eyebrows. Also has a diagnosis of TMD although this pain is less problematic.	GP ENT doctor	No	Sinus pain is not diagnosed but also has TMD.	For 10 years has lived with chronic pain, constantly devoting time and energy into finding ways of managing the pain.	Sinus wash Paracetamol Mouth guard Amatriptaline Chinese medicine
09 M	Sudden onset of pain, for no identifiable reason. <i>8 months</i>	Initially had excruciating pain on right side of face and jaw. Pain is now much less intense but still gets “twinges” and once a week gets an “attack”.	A&E GP Dentist Neurologist	No	Possible TGN	In the acute phase had to go to A&E as the pain was so bad. Now the pain has less impact but worries that it will return.	Tegratol Pregavelen Went to a trigeminal neuralgia AGM
10 F	Sudden onset of pain following particularly painful dental work. Has been in agony ever since. <i>1 year</i>	Describes jaw pain ‘morning noon and night for over a year’ Has seen numerous specialists and given conflicting information.	Dentists A&E Max fax neurologist	No	Possible TGN or atypical face pain	No longer has the energy or motivation to socialise. Feels like wants to go to sleep as soon as she gets home from work. Feels depressed and in ‘shock’.	Mouth guard Teeth removed and root canal treatment Prescription medications
11 F	Gradual onset of pain which has been getting progressively more intense and widespread. <i>20 years</i>	Pain in her TMJ, which is always present but varies in intensity. Additional toothache if she eats food which requires chewing.	Dentist	No	None	She has had to substantially change her diet and can only eat soft foods.	Mouth guard
12 F	Fairly sudden onset of pain following a bout of shingles. <i>2 ½ years</i>	Suffers from extreme pain in the side of her head. Able to gain some pain relief with medication, but struggles with side effects	GP Pain management clinic	Yes	Neuralgia as a result of shingles	Initially was exhausted and in agony, spending weekends home alone with the lights off. Is now coping better	Wide range of medications -with intolerable side effects. Keen to explore other treatment options.

Table 2 provides details of patients' pain experience: perception of how the pain began; a summary description of the pain; the types of professionals they had consulted prior to attending the pain clinic; and the different methods they have used to manage their pain. It shows that the sample is very mixed in terms of their journey to the pain clinic, with some participants having seen numerous professionals and others having been referred directly from a GP or dental practitioner. The wide range of pain management strategies employed is also striking and some participants had received invasive procedures such as tooth removal which were not successful in reducing the pain.

Self report data

As described above, the participants completed the HADS and BPI before and after their initial consultation at the pain clinic.

Table 3

HADS Scores Pre and Post Consultation. (moderate-severe scores are in bold)

Hospital Anxiety and Depression Scale				
participant	depression pre	depression post	anxiety pre	anxiety post
01	10	9	13	12
02	11	10	14	15
03	20	20	20	20
04	3	2	6	7
05	10	6	12	7
06	4	1	7	4
07	6	7	13	7
08	4	2	9	10
09	5	5	5	7
10	6	7	7	4
11	15	14	14	17
12	10	3	5	2
Mean	9	6	10	8
normal = 0-7; mild = 8-10; moderate = 11-14; and severe = 15-21				

The above table shows that before the consultation, three participants had scores the moderate-severe range for depression, and five for anxiety.

Disregarding a change in score of less than two in either direction, it can be seen that four participants were less depressed after their consultation. However, it is of note that none of these individuals had scored in the clinically moderate-severe range pre-consultation.

For anxiety, five participants were less anxious after the consultation, including Participant 05 who was initially in the clinically moderate-severe range. Two participants became more anxious post-consultation.

Table 4
BPI Scores Pre and Post Consultation (worst pain scores in the moderate to severe pain range are in bold)

participant	worst pre	worst post	average pre	average post	interference pre	interference post
01	8	7	6	6	8.2	6.5
02	10	7	8	7	6.5	4.7
03	10	10	7	8	9.4	8.2
04	5	6	2	4	2.4	1.7
05	4	5	3	2	1	0.7
06	6	3	4	1	3.4	0.4
07	8	8	5	7	3	6.4
08	7	3	5	2	2.8	0.8
09	2	2	1	1	1.1	2.1
10	9	9	7	7	6.2	6.2
11	5	4	5	3	2.1	0.7
12	6	7	4	5	4.1	3.5
Mean	6.6	5.5	4.7	4.0	4.2	3.1

Table 4 shows scores for “worst pain”, “average pain” and “pain interference”. For the BPI a score of two may be viewed as a clinically meaningful change (Cleeland & Ryan, 1994). It can be seen that three participants’ worst pain score and three participants’ average pain score decreased by a clinically meaningful margin following consultation. Two participants showed meaningful increases in average pain. For pain interference two participants showed a meaningful decrease following the consultation. Overall,

more participants showed meaningful reductions in anxiety and depression than on measures of pain.

Within subjects it can be seen that participants 06 and 08 showed meaningful reductions in each of the BPI scales, in addition to either reduced anxiety and depression (06) or depression (08).

Qualitative data

Analysis of the data resulted in 12 subthemes which were clustered into four key themes. These will be described below with illustrative quotes from the transcripts. Theme 1 describes participants' attempts to understand their pain, prior to their consultation. Themes 2 and 3 attempt to capture processes which developed over time and therefore contain subthemes from both the pre- and post-consultation interviews. Theme 4 relates to participants' expectations for the consultation and changes in their understanding of their pain and their way of relating to their pain that occurred following it.

Theme 1: Lack of information exacerbates helplessness

Theme	Sub themes
Lack of information exacerbates helplessness	Helplessness and hopelessness
	Uniqueness of orofacial pain
	Difficulties associated with lack of information and importance of professional input
	Information as confusing/ contradictory/ not fitting with existing understanding

This theme considers the impact that a lack of information had on participants' sense of helplessness and hopelessness that they alluded to during

the pre-consultation interviews. It also captures a sub-theme of participants sometimes finding the information they are offered difficult to accept.

A set of codes which appeared frequently across the majority of transcripts were about the helplessness and hopelessness of chronic pain.

“I don’t want to think ‘this is it’, sort of waiting to die to be out of pain, the next time I’ll be without pain is when I’m dead. I don’t want to be like that”.
(Participant 10)

“So it, it sort of feels as if I have to just wait, either till it gets worse, or it disappears on its own” (Participant 01)

It seemed that for some participants there was something specific to orofacial pain which made it especially difficult to cope with. One participant spoke about the location of her pain meaning that it often triggered sensitivity to light and additional headaches. Another person described both her sense of hopelessness and the nature of facial pain:

“It’s not even like if you hurt your arm you can hold it, I can’t even get to it... to sooth it. I keep thinking if it was in my leg, I’d just have my leg amputated. That’s it I’d just get rid of it, but you can’t get rid of your head. If this was in a limb and you could take it away, I wouldn’t think twice”. (Participant 10).

Analysis of the context in which comments about hopelessness occurred revealed that it frequently coincided with a lack of information about their

condition, such as not having an explanation for or guidance about managing their pain.

“It’s the limbo bit. That’s the bit that’s annoying”. (Participant 04)

A number of difficulties were associated with this lack of information such as worry that they might be exacerbating their pain.

“I found ... a video of exercises you could do, pushing your jaw in and out and I did try that for a week. My jaws initial reaction was a lot of pain but then it did seem to get a little bit better, I thought I don’t know if this is right or not for me, I’m not sure if I should be doing this... am I making it worse?” (Participant 06)

“I did think: I don’t want an infection. And I bought Orogel, it was all my own self medication. From there I started using that peroxide thing and I am absolutely sure that did something to my teeth. And then what I did notice was that it felt like they were losing their enamel” (Participant 07)

Some participants also believed that a lack of information has led them to become more sensitive to noticing pain sensations.

“It’s just that I’ve become very sensitive to finding a solution, I’ve become very sensitive to a load of things. So I’m feeling things that I generally wouldn’t have felt because I wouldn’t have been conscious of them.” (Participant 01)

All the participants described a strong desire to understand their condition better and many had gone to great lengths to search for information. Whilst several of them had tried to conduct their own research, almost all of them viewed personal encounters with professionals as the most valued source of information.

“Well, I just wanted to know that I’ve tried everything that I could. A lot of people would think dentist, max facs, neurologist was already over the top but I wanted to be certain that I’d tried everything.” (Participant 04)

However, it was clear that sometimes patients had been given information that they rejected for various reasons. Sometimes because it had conflicted with information other professionals had given them, but often it seemed that it just did not fit with their existing understanding.

“This neurologist thinks that I have to go over several months, to go right up from about 10mg to about 150mg but to me it doesn’t feel, doesn’t smack of something that would work on me.” (Participant 01)

“And uh, you don’t necessarily always want to tell them that they are in the wrong because they are the ones who are the doctors.” (Participant 03)

For others it seemed that an erosion of their trust in doctors or feeling dismissed by them had impacted on how likely they were to accept the information they imparted.

“Even my GP has turned round and said I’m imagining it, its not there. They’ve tried what they can and they just...[trails off and shakes head]” (Participant 02)

Some had heard difficult information about the prognosis of their pain but were able to accept this and use it to change the way they coped.

“I think the key bit of information [is that the pain may be long term] because ... for me to be sat inside all weekend, curtains closed. That was quite a shock really. If someone had said to me 6 months I’d think I can handle that. But if someone had said you’ve got to act like that for 25 years, I probably would have stepped things up a notch to try and find a way of getting round it, instead of wasting my time trying to sit it out.” (Participant 12)

However, sometimes participants later accepted information that they had initially rejected.

“I knew about this before as well, but to be honest I was reluctant to follow advice from psychologists, relaxation and so on. I knew about this before but I did nothing.” (Patient 11)

The transcripts suggest that patients may not always receive information as doctors intended it to be received. Therefore it seems to be not simply a lack of information that leads to hopelessness but a lack of “acceptable” or compatible information in the context of existing understanding.

Theme 2: Worry as part of the process of making sense of the pain

Theme	Sub themes
Worry as part of the process of making sense of the pain	Fear that pain signals something even worse than pain itself
	Fear that the pain persists because something curable has been missed

This theme relates to fears and beliefs about the causes of pain. There appeared to be a great deal of mystery surrounding pain and several had firm theories about its cause but scans or tests had disproved them creating further confusion. It also seemed that there was surprise that the face could be so painful.

“And surely these days with everything that can be done in the world, I mean they can transplant your whole face. Surely they can find [a cure]”. (Participant 10)

Perhaps in an attempt to make sense of this, participants tended to fall into one of the two paths subthemes above and this had consequences for how they lived with their pain. Only two participants did not fit this model. One already had an explanation for her pain that she was happy with (participant 12). The other (participant 07) tried to make sense of her pain by rigidly sticking to her original theory (mercury poisoning) and this arguably prevented her entering either of the pathways. Furthermore, some participants might have alternated between the pathways, but were more strongly identified with one than the other.

Participants who worried that their pain might signal something more frightening than the pain, such as MS, were not only contending with managing their pain but were also faced with worry about what their pain might portend.

“Also because pain can also be linked with other conditions like MS, so suppose it’s an early indicator of MS? I don’t know whether that’s a brain thing that the MRI can say if it’s not MS. But there is kind of extra worry on top of it as well.”

(Participant 08)

Other participants seemed to view the pain itself as the focal problem: for them, a consistent worry was that something fixable had been missed. This type of worry generally led to patients being unable to accept diagnoses or explanations from doctors, perhaps because they were not confident in either the doctor or the process by which used to make the diagnosis.

“Part of me thinks it’s that simple that everyone’s overlooking it. Maybe it’s that easy.” (Participant 10)

“Well, I’m just hoping that he’ll check the dental thing here, and he’ll double check that everything is clear here [touches sinuses area] yeah, and maybe if I get another scan”. (Participant 01)

Participants varied as to how preoccupied they were by such worries. Some seemed to constantly ruminate about their pain and others had, over time, developed ways of managing. Those that felt they were coping better tended to have found some way to prevent worry from interfering with their day to day life.

“When I first had it I got quite obsessive about it, always dwelling on it. Whereas now I can compartmentalise it in my brain, think ‘oh my jaw is hurting’ and put that to one side and get on with other things instead.” (Participant 06)

The consultation alleviated many of the participants’ fears, however this had very different consequences for participants depending on which worry pathway they were in. All those in the “feared something serious” pathway were able to stop ruminating about their worst fears and both BPI and HADS score reduced by clinically meaningful margins for two out of the five participants in this pathway following the consultation (participants 06 and 08).

Interestingly, there was little significant movement in scores on any of the measures for those in the “worried something fixable has been missed” pathway. It may be that for these individuals, receiving a diagnosis meant that they had to give up their hope for a “quick fix”. Following the consultation these participants had to come to terms with their pain needing long term management and they perhaps needed time to process this information.

Theme 3: Validation of the pain experience

Theme	Sub themes
Validation of the pain experience	Feel misunderstood and dismissed
	Desire to make the invisible pain visible
	Importance of diagnosis

This theme describes the observed importance participants placed on having their pain experience validated by the pain clinic staff. Many participants worried that because their pain was invisible and did not have a label, others might think they were making it up; some even reported worry that they might be

exaggerating it in their own minds. It may be that it is even more difficult for patients to explain orofacial pain to others than pain elsewhere. Other than dental and sinus pain, there did not seem to be a shared concept of facial pain that patients could use to explain their experience to others.

“How do I know I’m not making it up? I don’t know, maybe I’m making it up. There is no visible evidence of what is going on here.” (Participant 06)

“You have something that to you is very painful, but actually doesn’t seem it to other people. I mean there is no reason why other people would think there is anything wrong with me. I can walk, I can go and get myself a drink, I am totally normal and yet, only I know the pain.” (Participant 07)

A theme common to many of the participants was a desire for some sort of visual proof of their pain experience.

“It’s disappointing when I go for blood tests and they say everything is fine.” (Patient 03)

“I’d like to get a Stanley knife and cut the side of my face open so I could see what is in there. That’s the only way you’re going to see” (Participant 02)

“A couple of weeks ago a woman that I manage said that my jaw looked swollen and it was the first time someone said it looked different. And I nearly kissed her, I thought ‘you can see it?!’ Because no one can see what I feel.” (Participant 06)

This desire for pain to be made visible appeared to have several functions for participants: validation and confirmation of the reality of their pain, a very private experience; and entitlement to seek support and access to support of others with the same identified problem.

“Maybe then [if I had a diagnosis] there are things I can do like support groups, I don’t even know if I would want to go to one, but knowing that they are there, that there is an option, some sort of community spirit thing. (Participant 04)

However, several participants also alluded to a belief that a positive test and/or a diagnosis would automatically lead to a cure.

“But on the other hand if it was there [on the scan] at least I’d know there’s something that can be done about it.” (Participant 08)

“If I know what it is that would help me manage the pain in some way.” (Participant 05)

Another common expectation was that diagnosis would involve scans and tests and consequently several were surprised that much of the diagnostic process was based on history taking. However, almost all the participants were able to accept the diagnosis and explanation given to them. Furthermore, diagnosis did not lead to a cure being identified but it did appear to alleviate people’s worry...

“I was quite relieved to have a diagnosis...although I had hoped I would come away with a solution for a cure, I am happy now that I know the cause and that it is not serious”. (Participant 05)

...and enable some to give up what had been an exhausting search for answers.

“It’s not clutching straws wondering what’s going to happen next? Or who I’m going to see next? Are they going to operate? Are they going to do this? I’ve been told there is nothing they can do, so that’s put it to rest so to speak... It’s just something I’ve got to learn to live with now.” (Participant 02).

“I guess what the appointment has done is drawn a line under it and made me think, well that’s fine but nothing can be done about it so I just need to get on with things.” (Participant 09)

Overall, it seemed that the all the participants had been seeking some sort of certainty, in diagnosis, prognosis and, for some, the legitimization of their pain. That they were able to accept these again appears to be linked to the processes described in the following theme based on prestige and trust.

Table 5
Summary of Expectations of and Reflections on the Consultation

Name	Hopes and expectations for consultation	Diagnosis given	Thoughts on consultation	Changes following consultation
01	To have teeth and sinuses checked, preferably including a scan. Thinks a sleeping pill prescription might be helpful.	None but has a second consultation to go to.	Surprised by volume of questioning but found he had time to explain his situation and this was listened to. Had expected there to be scans, stethoscopes and more “prodding”. Was left a little disappointed.	Feels nothing will change as still doesn’t have a diagnosis and hasn’t had a scan.
02	To achieve at least a substantial reduction in pain and get a diagnosis.	Nerve damage	Pleased that everything was explained in layman’s terms. Despite hearing there is no cure he appreciated the honesty. Overall very satisfied and relieved the doctor did not think he was imaging the pain.	Has a new understand of the cause of his pain. Will focus on pain management and will not pursue any other operations.
03	Has low expectation as has been let down before but is hoping to have all her fillings removed and replaced with non-mercury ones.	Doesn’t know	Feels the questionnaires prevented her expressing herself. Was left frustrated and angry. Found the doctor as being disinterested in what she tried to tell them as she did not agree with her theory of mercury poisoning.	None.
04	Desperately hopes to see Prof. Zac. Is expecting a diagnosis and advice on pain management. Is concerned that it will be difficult to accurately convey her pain experience to the doctor.	Trigeminal neuralgia	Was pleasantly surprised by the length of time the doctor spent with her and felt understood and listened to. She found receiving the diagnosis very helpful.	New understanding of cause of pain and better prepared to cope with symptoms. Initially pleased to get diagnosis but later felt a bit overwhelmed.
05	Would like to know what is causing the pain and wants an x-ray. Prepared to accept pain if this doctor can not find a cure.	None	Found it frustrating the questions seemed to repeat those she had answered on the forms already. She received an x-ray which put her mind at rest that there was no visible damage. She found the process impersonal.	Change in her understanding of why she might have pain but does not think she will follow the pain management.
06	Looking for advice on management and reassurance re fears about e.g. abscesses on his jaw. His main worry is that he might get referred on again, delaying treatment.	Chronic facial pain	Felt that there was no opportunity to explain his pain experience in his own words but that the questions asked were comprehensive. He valued the explanations about the cause of his pain and how to treat it. Overall he states the appointment was a success.	Large shift in his understanding of the cause of his pain. He is following the new treatment plan and is feeling much more positive.

07	Wants to receive a diagnosis and treatment for both the condition that is causing the pain and to repair the damage caused to her teeth. Feels optimistic that this clinic will listen to her.	None but has been referred for restorative work.	She was surprised at the ‘quick fire’ questions and that there was little room to explain in her own words. The doctor had some understanding of her experience but overall did not find it helpful.	Does not feel she has learned anything about what is causing her problem and is frustrated at being referred on.
08	Would like a diagnosis and guidance on treatment but is not necessarily expecting a cure.	Damage caused by a sinus wash-out procedure	Describes it as “extremely constructive, thorough and helpful”. The explanation was clear and was relieved to finally receive a diagnosis and reassurance that the pain was not the result of anything “serious”.	Has a new understanding of the cause of her pain. Will introduce some new pain management strategies
09	Very keen to see Prof Zac. Is expecting to have his suspicions that his pain is ‘atypical’ confirmed and that there is no cure for this but would like advice on management. He would like the doctor to give him a dental check.	Infected, fractured molar.	It involved less actual testing and more verbal discussion than expected but found it helpful that his previous MRI results were explained to him in more detail than he had previously received.	Will be worrying less about the pain as his concern that he had trigeminal neuralgia have been substantially reduced. He thinks he is noticing the pain less.
10	Is keen to see Prof Zac and hopes an explanation of her pain. She has never had any scans and would like this done in case something fixable has been missed.	Trigeminal neuropathic pain	Felt the diagnosis and future expectations were clearly explained to her. Expected to receive more scans and was upset not be diagnosed without one.	She has a better understanding of the cause of her pain and its prognosis. Will now focus her energy on looking after herself rather than pursuing answers.
11	Is hoping that the clinic will be able to repair her teeth but is not optimistic that they would be able to help prevent further damage. .	Confirmed that teeth are worn away by grinding and clenching.	She felt the doctor understood her difficulties and that the information she was given was useful. Commented on feeling uncomfortable that another healthcare professional was in the room.	Is more aware of the importance of actively involving herself in the management of her condition.
12	She would like the doctor to explore jointly with her treatment options other than medication. She already has a diagnosis and feels fully informed about her condition. Her main concern is that the doctor takes time to understand her situation.	Original diagnosis confirmed.	Frustrated that the appointment was about confirming her diagnosis and her wish to discuss treatment options and become more involved in treatment planning was not met.	Will not be making any changes and feels she will have to explore alternative treatments herself. Did learn some new facts about nerve damage.

Table 6 above, provides a summary of participants' expectations for the consultation, their reflections on it, and the changes that occurred following it. It can be seen that some received a new explanation for their pain which they appeared to take ownership of, and for these individuals the consultation enabled them to develop a new understanding of the cause and maintenance of their pain. Others had new plans for how they would manage their pain or had become more positive and less worried about their pain. All but one participant (03) perceived that the consultation had resulted in some change for them. The final theme attempts to capture both the changes that occurred and the factors that enabled change to occur.

Theme 4: The importance of trust

Theme	Sub themes
The importance of trust	Expert status attributed to the clinic
	Acceptance of diagnosis and prognosis without the hoped for scans
	The giving up of invasive treatments, searching for answers and worrying

The final theme relates to participants' expectations for the consultation and changes that occurred following it.

Unsurprisingly, in the first interview all the participants held expectations about receiving a diagnosis and learning how their pain could be treated, and many were expecting to have scans. Of particular interest, however, was that there was often a sense of optimism about the forthcoming consultation, not that their pain would be cured, but that they would finally gain the information they were seeking, be that a diagnosis, an explanation, or specific guidance on pain management. Sometimes this was combined with a specific desire to be seen by the lead

consultant¹, suggesting that patients viewed her and sometimes her clinic as having expert status:

“Its about the only time I’ve ever felt, this could be the one. Purely because I’ve heard so many good things about Professor Zakrzewska” (participant 10)

After the consultation, the majority of patients reported that some sort of change had occurred as a direct result of the consultation. For some this was having a new understanding of their pain; for others it was abandoning the pursuit of invasive treatments or answers, and a number of patients described having had their minds put at rest or feeling more able to cope.

“Even though I haven’t come away with a cure, I feel in a better position to cope with my symptoms”. (Participant 04)

“I don’t think I had even considered the possibility that my pain could be related to something else and not in my jaw. I found this quite surprising and it has taken me a couple of days to get used to the idea....I have also noticed a difference in how positive I feel”. (Participant 06)

That these changes occurred implicitly demonstrates that these patients trusted and accepted the information given to them during the consultation. Furthermore,

¹ The lead consultant at the pain clinic, is an international expert in the field. She has published books several books aimed at patients, some authored jointly with patient groups, and is therefore more well known than the other pain consultants at the clinic and written about on patient websites.

even though many of the patients had originally wanted scans carried out, most were able to trust the doctor without one. This appeared to be a combination of feeling that the doctor had listened to and understood them, having the diagnosis clearly explained, and the expert status attributed to the clinic.

“I felt the Professor listened to me more than the other healthcare professionals I have seen and took into account the effects the pain was having on my life in general, rather than just treating me as a diagnosis” (participant 04)

“I think it was the way it was explained. It was explained on my level, so to speak. There were no big medical terms, it was explained in an easy way that I can understand” (participant 02)

“[the diagnosis] just wasn’t what I was expecting, but it makes a lot of sense and I definitely trust her diagnosis” (participant 06)

There were however exceptions to this: three participants were left disappointed by the consultation and felt that it had not led to any changes for them. Examination of these transcripts reveals that two had both had very specific hopes and expectations for the consultation which were out with the remit of clinic provision. One (participant 03) had a very fixed theory about mercury poisoning and wanted this theory verified and her fillings removed. The other (participant 12) already had a diagnosis and was well informed about her condition and its prognosis; she had hoped to discuss treatment other than medication. The third (participant 07) just did not feel her expectations had been met.

Dissatisfaction was expressed by some participants about elements of the consultation style, such as doctors not introducing themselves, which then impacted on patients' overall experience of the consultation. Often these feelings of frustration were contained within the written narrative with a significant degree of affect apparent. This feedback will be given directly to the clinic.

Discussion

The following section will discuss the main findings in relation to both the study aims and other relevant clinical research. The strengths and limitations of the study will be considered followed by the clinical and research implications of the findings.

Summary of main findings

Pre-consultation, frequent experiences shared by the participants in this study included feeling helpless and hopeless, and fearing they were inadvertently making their pain worse. All of this was exacerbated when participants perceived themselves to lack information about their condition. Importantly, however, diagnosis and information alone were not enough to enable all participants to feel they fully understood their pain, as the receipt of new information was coloured by a number of factors including their existing understanding of their pain.

It emerged that the participants engaged in processes, occurring over periods of time, which involved worry (depicted in Diagram 1, below), seeking validation and searching for information (depicted in Diagram 2, below) as they attempted to understand their pain. Common fears were either that something curable had been missed, or that the pain signalled something more serious. It seemed that those in the

latter group were more likely to be able to reduce the extent to which pain interfered with their life following the consultation.

Pre-consultation, many of the participants were keen to have scans and tests to validate their pain and several held erroneous beliefs that diagnosis would imply probable cure. Even though scans and testing were not part of the diagnostic process and labels did not lead to cures, explanations of the pain did have several important functions for participants, including the alleviation of worry and abandoning the pursuit of explanations from multiple sources.

Almost all the participants experienced some sort of change following the consultation, mainly around their understanding of the cause of the pain or their intentions for pain management. Importantly, it emerged that the prestige attributed to this particular pain clinic enabled most participants to accept diagnoses and prognoses and take ownership of new understandings even without the hoped-for scans and tests. This led to these patients letting go of their worries and giving up what had often been an exhausting pursuit for answers. A further change that occurred following the consultation was an overall reduction in the participant group's anxiety, depression and pain interference scores.

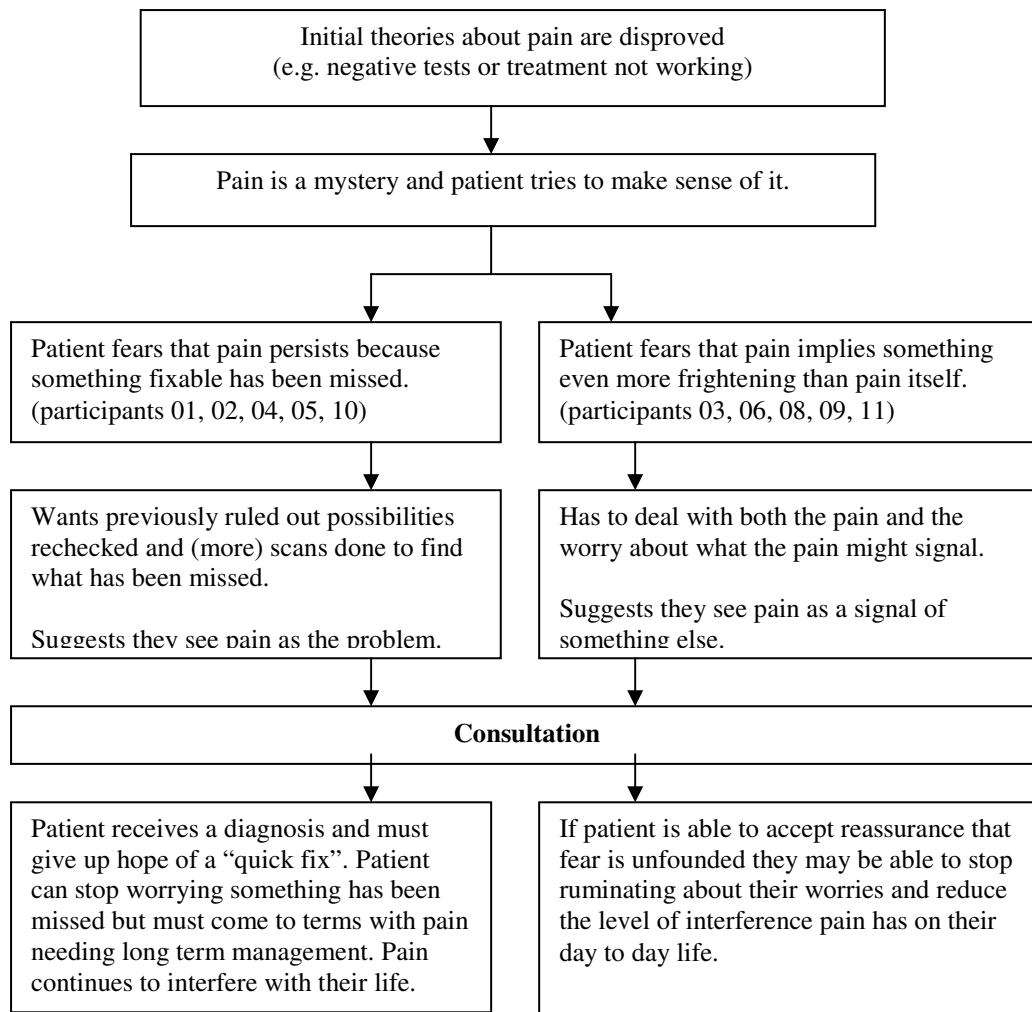


Diagram 1 The process and content of worries about pain

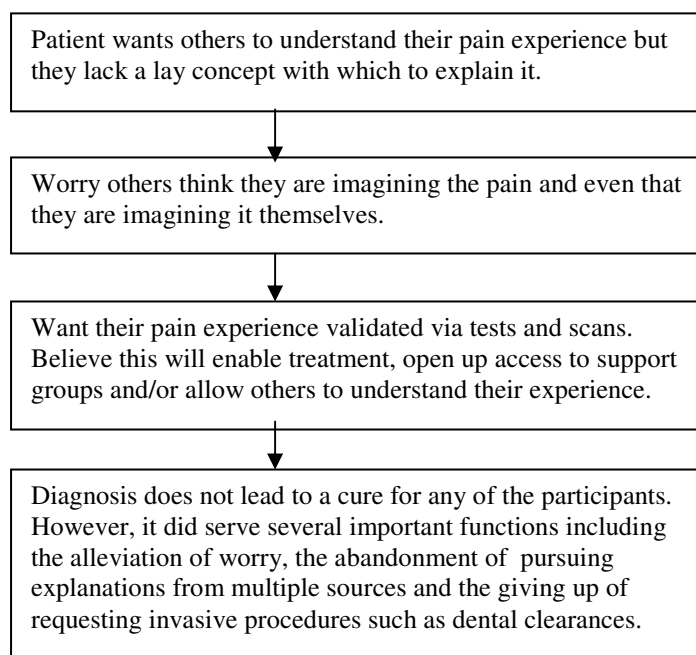


Diagram 2 Process of having pain validated

Comparison of findings with other research

Worry.

In this study, worry was common and emerged as part of the process of trying to understand pain. This is in line with research that has shown that patients are especially prone to ruminating about their pain when the cause is unknown (Eccleston et al., 2001; Morley & Wilkinson, 1995). This study suggests that the process of worry serves to help patients understand their pain and, by worrying about something curable having been missed or their pain signalling a frightening disease, it also ensures they direct efforts towards obtaining appropriate assessment and treatment.

However, it has been shown that for individuals with chronic pain, worry can become “misdirected” trapping them in a process of repeatedly attempting to solve the wrong problem (Eccleston, et al., 2001; Eccleston & Crombez, 2007).

The processes of worrying described above also meant that participants had to contend with both pain management and their worries about what the pain might mean. That the majority of participants in this study were able to reduce worrying following their consultation at the pain clinic suggests that “acceptable” information can help alleviate worry. However, when patients have a lack of information, are given information that either does not fit with their existing pain model or contradicts information from one of the many professionals they had already consulted, new information does not necessarily bring a resolution of worry, but can create further confusion and perpetuate cycles of worry.

A better understanding of how patients can be supported to reduce worrying is important in light of findings from other research which shows that worries about pain are more difficult to dismiss, more distressing than other worries and can exacerbate suffering (Eccleston et al., 2001). Pain related fears are also easy to

acquire but difficult to extinguish (Hermans et al., 2005) and worrying about chronic pain maintains vigilance for pain and other somatic sensations (Eccleston et al., 2001), including those of no significance.

This study also found that one of the difficulties associated with having a lack of information was a fear of inadvertently exacerbating pain due to not knowing what is and is not safe to undertake. This is in accordance with studies of other types of chronic pain, particularly lower back pain, where fear of pain has been shown to lead to guarding of painful parts and avoidance of previously valued activities, leading to physical de-conditioning (Vlaeyen & Linton, 2000). Furthermore, in their fear-avoidance model, Vlaeyen and Linton (2000) propose that fear also increases hypervigilance and can contribute to the persistence of chronic pain conditions.

It may be argued that there has been under-recognition of the importance of helping patients to understand their pain in attempts to reduce pain-related fears and worries. Reassurance is used by medical doctors to minimise patients worries, but its effects have been shown to be inconsistent, transient (Linton, McCracken & Vlaeyen, 2008) and increase urges to reassurance seek (Salkovskis & Warwick, 1986).

Importantly, when patients visit GPs with unexplained symptoms, (pain is the most common) they seek information, advice and recognition of their distress. However, doctors mainly provide referral and prescription (Gask & Morriss, 2008; Salmon et al., 2007), meaning that many patients arrive in secondary care feeling not listened to and lacking information, as did the participants in this study.

Helping patients to reduce fears and worries will be more helpful when guided by theories about learning and behaviour change. These theories suggest that for reassurance to be effective doctors must take into account the patient's existing

understanding as well as aspects of the way the communicate information, such as the use of empathy (Linton et al, 2008).

Coping.

This study identified that worry was a common process but that participants varied on how consumed they were by worry and how well they felt they were coping with chronic pain. Exploring the reasons why some people coped better than others was not the focus of the interviews, but some participants found that information about the cause and prognosis of the condition from a trusted source helped reduce worrying and therefore impacted on how well they coped with their chronic pain.

Another qualitative study which explored lay views of pain relief clinics found participants fell into one of two categories: those that were dominated by their pain and those who had found ways to distract themselves from their pain and develop a more integrated view of the effect of pain on their lives (Bendelow & Williams, 1996). The latter group were more likely to have had their pain for a shorter time period and to be middle class. This highlights that information and advice from a pain clinic alone does not necessarily lead to better coping. Instead, a number of other factors such as past experiences and social class may shape the way information is received.

Acceptance.

Previous research has demonstrated that acceptance of chronic pain, which involves a willingness to engage in valued life experiences, without attempting to control or avoid pain leads to better emotional, physical and social functioning (McCracken & Eccleston, 2005). The same study proposed that patients who are less accepting of their pain seek more medical consultations and request more medication, over longer periods of time.

This study found that receiving a clear explanation about their pain and its prognosis helped some participants make positive changes to their lives such as to stop worrying, and give up on their exhausting pursuit for a cure. Their descriptions of planning to “get on with life” after receiving, often difficult news about the prognosis of their condition, appear to be in line with McCracken’s definition of pain acceptance.

Furthermore, by expressing a desire to “get on with life” in spite of knowing that their pain is unlikely to remit, these participants appear to have “reframed” their pain problem. Importantly, this is held to be essential if a patient is to find a way out of the negative cycle of worry associated with chronic pain (Eccleston et al., 2001). Moreover, the concept of pain acceptance may help explain this study’s observed reduction in BPI and HADS scores

Validation.

This study found that participants were keen, sometimes desperate, to have their pain experience validated. The lack of a common lay concept for facial pain appeared to exacerbate this need as several people spoke about feeling unable to talk to friends and colleagues about their pain, thus excluding them from social support. Furthermore, some participants had even started doubting whether *they* might be imaging the extent of their pain. Almost all the patients hoped for scans and tests to be carried out, even though pain is only very weakly related to structural problems revealed by scans.

Another qualitative study, conducted on a group of patients with chronic back pain concluded that testing constituted the route to legitimization of the chronic pain experience. When their pain could not be located on a scan patients felt that their pain

had been disconfirmed, leading them to feel a sense of deficiency and shame (Rhodes, McPhillips-Tangum, Markham & Klenk, 1999).

However, by following up participants who had hoped for scans, but who instead received a consultation based around history taking, this study was able to explore participants' responses to this. Importantly, many of these participants were able to feel satisfied with the diagnosis and explanation of their pain that they received. This appeared to be due to a combination of feeling that the doctor understood them, having the diagnosis clearly explained and the expert status attributed to the clinic.

Reflections

A strength of this research is that it specifically investigates orofacial pain, a group of chronic pain patients which are sometimes thought of as being different to and more psychologically disturbed than other pain groups (Newton-John, 2002). This study was able to show that these patients are likely to express similar fears and beliefs to other pain patients. However, it was additionally able to highlight that there are some aspects of orofacial pain that patients find particularly distressing: for example, one participant said it was harder to hold and soothe a face.

Moreover, by collecting information at three different time points this study was also able to chart changes in fears and beliefs over time and to consider the impact of a consultation at a specialist pain clinic.

In considering the usefulness of the methodology adopted, it is of note that it became necessary to combine the data obtained from the written narratives and post consultation interviews, as described in the methodology. However, whilst the unique contributions of these two data collection methods are not apparent within the results,

reflecting on how different participants responded to the different tasks enables some interesting hypotheses to be drawn.

It emerged that many of the written narratives contained lengthy descriptions of the process of the consultation, sometimes with a notable level of affect expressed regarding elements of it that had been experienced as frustrating or upsetting. It may be that because these narratives were written immediately after the consultation, participants felt a need to vent their feelings. Whilst this information about how participants experienced the consultation was valuable, it did not fully address the aims of the study. Much of the data on changes in fears, beliefs and understanding came from the post consultation interview.

It may be that the additional week that passed before this was written enabled participants to be more contemplative about change, or perhaps the structure of the interview was necessary to supported participants to reflect in a way which is arguably not common practice in medical settings. Therefore, in retrospect, it may have been better to have swapped the position of the written narrative and second interview: to have conducted the telephone interview the day after the consultation, providing a space for the expression of any frustration and the opportunity to prompt reflection, before giving the participants a week to complete the written narrative.

Limitations.

The main weakness of this study was that it was not possible to control which doctor the participants saw for their consultation. This means that they may have received slightly different styles of consultation and pain explanations.

Furthermore, the follow up interview and completion of the measures took place one week after the consultation and it is not possible to say whether the changes in mood, worrying and understanding will be sustained over time, or may improve or

deteriorate. In common with all patients at the clinic, there were a range of options for the participants with some being referred onto e.g. a pain group, but several receiving no further input. It is likely that each individual's trajectory after the consultation will continue to shape their understanding of pain but it was not possible to explore this in the present study. It could however, be hypothesised that participants left their consultations feeling more positive, but that if they are unable to integrate their explanations or to make changes to how they manage pain so it interferes less in their lives, hopelessness might return, and depression and pain interference scores might increase again.

Lastly, although it subjectively seemed that data saturation had been achieved with 12 participants, having a larger sample group would have enabled comparisons to be made in the responses of, for example, men and women or different age groups.

Clinical and Research Implications

The consultations in this study were, on the whole, successful at alleviating worry and enhancing participants' understanding of their chronic pain. This underlines the importance of providing patients with an explanation of their pain in a way that they can understand and take ownership of. However, many of the participants had seen a large number of professionals and suffered for long periods of time before being referred to this clinic. It would therefore be of clinical utility to identify what it was that enabled some participants to accept the explanations they received here and consider how this might be done at an earlier stage. It is also important to reflect on the minority of participants who were left frustrated and unsatisfied by the consultation.

In line with other research that describes the extent and nature of worry about chronic pain, participants in this study engaged in a process of worrying about the meaning of their pain which added to their distress. The two key worries identified were that something fixable had been missed and that pain might be signalling a serious disease. If these could be verified as being commonly occurring worries in a larger sample group, perhaps doctors at a tertiary, or even primary care level, could enquire about and find a way to directly address these worries.

This study was also able to challenge the common assertion that patients cannot feel their pain has been validated until they receive a scan which visually objectifies their pain. A valuable next step would be to investigate how the factors that enabled this to happen could again be brought in at an earlier stage. Whilst the prestige of the pain clinic and its lead consultant may be difficult to replicate, a consultation style which enables patients to feel fully understood and which provides a comprehensive explanation of chronic pain may be more attainable.

Finally, consideration of the participants who were unhappy about the consultation and who were not making any changes as a result of it, revealed that they had very specific expectations which were out with the remit of the clinic. This information will be fed back to the clinic, possibly enabling them to triage such patients differently or to open discussions about how such scenarios could be managed differently.

Conclusion

This study has shown that whilst orofacial pain patients often have some unique experiences (including long journeys involving many professionals, a lack of a

lay concept for facial pain and particular difficulties with soothing their face) on the whole they hold similar fears and beliefs to other chronic pain patients.

It has also demonstrated that patients' fears and beliefs about chronic facial pain develop over time, and through processes of worrying and searching for meaning. Whilst a lack of information can exacerbate hopelessness, educating patients on their chronic pain condition can only achieve its aims when patients feel understood and trust their doctor. Despite patients frequently hoping for tests to validate their pain this study has shown that when diagnoses are delivered sensitively and explanations are given clearly, patients can make changes to the way they make sense of and manage their pain, and the degree to which pain interferes with their life.

That a single consultation can effect the significant changes described above underlines the value of the service provided by the facial pain clinic and it would be of great value to find ways of harnessing the mechanisms that enabled change so that they can be integrated at earlier stages of patients' pain journeys.

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PART 3: CRITICAL APPRAISAL

Introduction

This critical appraisal contains my reflections on the process of conducting my major research project, beginning with a description of the thoughts and worries I had about the topic. I then reflect on the obstacles I faced during my literature review and explain how I worked through these. The next section considers the process of carrying out the empirical paper. It reflects on the potential impact on the participants of taking part in my project and explores my experience of conducting the interviews. Finally, it discusses possible ideas for further research.

Conducting the major research project on an unfamiliar topic

At the point of choosing our thesis topics, health psychology was an area that had received hardly any attention in the teaching, but I had always held an interest in the area and I hoped that carrying out a thesis which incorporated some aspect of physical health would provide a fantastic opportunity to learn more about it.

I had originally set out to conduct my research in paediatric psychology, but the idea for this project turned out not to be viable. When I approached Amanda C de C Williams to discuss her ideas for research I therefore felt I had fallen behind in the process of putting together a thesis proposal. Furthermore, although I found Amanda's initial ideas for the study extremely interesting, chronic pain was something I knew very little about. As I started reading various books and papers I realised that I was worryingly unfamiliar with the key theories and models of chronic pain.

It felt very daunting to be putting together a proposal on a topic that was so unknown to me, but on the other hand, the suggested research question had really captured my imagination and I was attracted to the idea of qualitative research.

Despite the obvious challenges of getting to grips with a new area it felt like I had found a project which would sustain my interest over the following two years.

Literature review

I set about reading as much as I could on chronic pain and noticed several indications that there was a relationship between chronic pain and socio-economic status (SES). I have always been interested in health inequalities and I decided that exploring the relationship between SES and chronic pain would be the focus of my literature review.

My initial scoping exercises to identify relevant research indicated that there had been a number of large scale epidemiology studies carried out in chronic pain that explored potential contributory factors, one of which was often SES.

One of the first difficulties I encountered however was that SES was often poorly defined and measured, particularly in the large epidemiological studies in which SES was just one of a many variables under investigation. Often only one marker of SES was used and chronic pain was defined in a variety of ways, with several studies choosing to measure disabling pain instead and others not discriminating between acute and chronic pain. This made the process of deciding which studies to include difficult as I did not want to include studies in which the measurement of SES or chronic pain was not methodologically sound enough to be useful.

A further problem emerged after I had run all my searches and collated a group of studies to include in the review. I was aware that chronic pain had a number of names such as chronic musculoskeletal pain and persistent pain, so I had selected my search terms in an attempt to capture studies using any of these terms. However,

after reading a number of the studies identified by my search criteria, I found several more useful ones by trawling their reference lists. I realised that many studies that were actually measuring chronic pain had called it by completely different names that my search criteria had not picked up, such as disabling pain, hip pain and back pain.

I started to panic that the search terms I had used must have been hugely ineffective if I had been able to identify six new papers by trawling reference lists and I wondered how many more studies might exist that I had missed. I realised that I would have to systematically run the searches again using each of the new labels for chronic pain I had come across. Whilst this was a time consuming process and my confidence in my literature searching abilities had taken a knock, I discovered that other than the six studies I had already identified, there were no other relevant papers.

A further difficulty was that as I identified and read better quality studies, I was struggling to fully comprehend the findings. Clearly this was because the papers were written from an epidemiological standpoint and I wondered whether or not I was going to be able to review studies from a discipline I have no training in. I persisted but it took much longer than anticipated to categorise and summarise all the relevant studies.

My main discovery at this stage was that the literature provided strong evidence of a relationship between chronic pain and SES, albeit one which was not direct but influenced by a number of factors. However, none of the papers offered any real comment on what the psychological meaning of these findings might be and I was aware that in order for the review to be relevant for a clinical psychology doctorate I had to bring a psychological perspective into it. I clearly remember feeling very stuck at this stage and having no idea how to write the discussion.

I took several weeks away from the literature review before considering that the reason I was so stuck might be because there was actually no overlap between the work epidemiologists and psychologists were conducting in the area of chronic pain. However, I also started to realise that a review which highlighted and attempted to bridge this gap might be a useful piece of work to produce.

I also recognised at this point that I had become so immersed in the very specific chronic pain and SES studies that I had forgotten about the more general health inequalities literature. Whilst there are no clear cut answers in this either, much more work has been done on examining the psychological meaning of the association between poverty and poor health. I was able to find inspiration and guidance from this to make some attempts at linking together the very separate literatures from the epidemiologist and the psychologist research canons.

Having now finished the review I am able to look back and feel very satisfied with the end product, in spite of the difficulties encountered along the way, and I hope that it has started to bridge an important gap in the literature.

Empirical paper

Consequences for participants

This next section focuses on some issues that arose during the process of designing and carrying out my empirical study. It starts by reflecting on the potential impact for participants of taking part in qualitative research on chronic pain, and it highlights different points of view on this topic.

Having defined a research question for my empirical paper, one of the next steps was to work with my supervisor to develop the methodology. As we wanted to examine how patients' fears and beliefs might change following a consultation at the

pain clinic it was decided to interview them before their consultation, ask them to produce a written narrative immediately after it, then complete a follow up interview a week or so later, in addition to pre and post-consultation self report measures. We felt that these three points of data collection and three different methods would enable particularly rich information to emerge.

Conducting research involving patients in an NHS hospital however meant that I had to have my study approved by the service and its managers, and this resulted in concerns being voiced that the patients might find the process of talking about their pain distressing. Conversations took place about what procedures I would put in place to support individuals who became distressed by the interviews. Coming from the position of being a clinical psychology trainee, I held beliefs that talking about problems was generally helpful when done in a supportive environment and I was surprised by the concerns.

There were also several aspects of the ethics application process which were more time consuming and complicated than I had initially anticipated. Despite this, once I eventually submitted my ethics application, the committee passed it. I was left feeling a huge sense of relief, but curious about the concerns that had been raised along the way. Consequently, I decided that I would ask each participant to reflect on the process of taking part at the end of their first interview as I was interested in what the process really would be like for them. This proved to be a very useful exercise, as I discuss later.

With hindsight, I could have been more assertive when I encountered obstacles in the ethics application process such as being more persistent in requesting face-to-face meetings to discuss the issues and therefore resolve them more quickly. Having been through all of this I would certainly do things differently if I face similar

problems again in the future. However, the experience has also lead me to appreciate how easy it can be for interesting research projects to never materialise.

Before starting the recruitment I also had concerns of my own. I worried that my three stages of data collection would be asking for a great deal of effort and time from patients, particularly as the specialist nature of the clinic meant that some would be travelling from outside London. To my surprise, however, recruitment was relatively easy. I sent out invitations to participate and information sheets detailing the study in batches of approximately twenty and received an average of four interested patients from each batch. Although not everyone who responded was able to participate for practical reasons, all of those who signed a consent form to take part completed the whole process and no one dropped out.

Furthermore, my enquiries into how participants found taking part in the interviews revealed that everyone found talking about their pain helpful, despite all expressing fears and worries about their pain. There were two people who became tearful during their interviews because they found the impact pain has had on their life so distressing to describe, but similarly to all the other participants they reported that the experience of having had someone listen to them carefully had been comforting and refreshing. Several participants said that the initial interview had helped them to think about their pain in a much more organised way and some even reported that they felt better prepared for their consultation as a result.

I was curious about this unanimously positive reaction to taking part, partly due to the initially cautious attitude my study had evoked and also because the interviews had not been therapy sessions; they had simply been information gathering sessions.

I wondered whether sceptics might argue that the participants might have found it difficult to say to me that they had not liked the process, but I had been careful to phrase my questions in a way that meant I was not asking for feedback on my interviewing skills and also encouraged them to speak about anything that had been uncomfortable to discuss. Two patients told me that they did not like talking about what they believed to be the original cause of the pain (for one this was an assault and for another it was some form of undisclosed trauma). However, this was not the focus of the interview and we had not dwelt on these issues, and so it did seem that people had genuinely had a good experience of talking about their pain.

I wondered whether the apprehension about me speaking to patients about their pain, which had come entirely from a medical doctor, perhaps exemplifies a preference within medicine for patients to censor emotional expression. Furthermore, the basis of concern seemed to be that if patients got upset they would want to complain (which is why I was told to offer anyone who was upset a meeting with the lead consultant). In fact, my observations were that patients valued the opportunity to have someone listen to them and support their thinking about their health problem, specifically because the problem had an emotional component to it. Consistently, research has found that often patients look for support and understanding from healthcare professionals, rather than simply diagnosis and treatment (Barry et al., 2000).

Still curious, I searched the literature and found that some experimental research has explored why talking about difficulties appears to be helpful. Research using fMRI suggests that putting feelings into words may activate the right ventral lateral prefrontal cortex, which may in turn suppress the amygdala, the area of the

brain that is important in processing emotional distress, particularly fear (Eisenberger, Lieberman, & Williams, 2003; Lieberman et al., 2007).

Despite resolving the issue of whether participants would become distressed by talking about their pain, the process of conducting the interviews raised another concern of my own. During one of the interviews a participant explicitly said to me that she was desperate to see the lead consultant of the clinic and was hoping that taking part in the study would increase her chances of being seen by her. Unfortunately for her, this was not the case: interviews had no influence at all on the care patients received at the clinic, and despite the fact this was stated in the information sheet the participant still held that hope. A significant proportion of the participants had also spoken about their desire to see the professor and although they never voiced it, I wonder in retrospect if this might also have influenced their decision to take part. That said, none of the participants voiced being unhappy about the doctor they saw, however, in future I might be more careful to dispel any potential erroneous beliefs at the point of taking consent.

Reflections on the content of the interviews

This section reflects on the process of conducting the interviews and the nature of the information I obtained.

The interviews I conducted were guided by a semi-structured interview schedule that I developed with the support of both my supervisors. I remember my first interview very clearly, not least because the fire alarm sounded just after I asked the first question and we had to evacuate the building! My participant told me he was not prepared to wait and would go for a walk instead. I was sure that would be the last I would see of him, but he did return and he provided not only very interesting

information for the study, but valuable interview experience for me. After our meeting I quickly typed up the transcript and my external supervisor, Jenna Love, helped me to review my interviewing technique.

One of the key things I changed after my talk with Jenna was to refrain from sticking too closely to the structure in the schedule. There was an occasion near the start of that first interview where the participant started to tell me about something I was planning on asking him later on. I acknowledged that what he was saying sounded very relevant but asked him if we could come back to it. I later reflected that it might be more helpful to allow the participants to tell their story in whichever order feels most comfortable for them as this is likely to as much detail as possible to emerge. Of course, as I became more familiar with the interview schedule I was able to be more confident that I would not forget any of the topics I needed to cover and could weave the questions into the conversation in a more natural way. I think that has been a useful skill to develop both for research interviews and clinical work.

After the first interview it was apparent that I would not have time to type up every transcript before the next interview, but on the advice of my supervisor I took time to listen back to as much of the recording as I could and made notes on the interview. These helped me to refine my interviewing style and also to develop new areas of curiosity which I could then follow up with future participants. For example, I noticed one participant using his knowledge of another chronic health condition he had to help him understand his pain better, so when I interviewed subsequent participants with comorbid chronic health conditions I briefly enquired whether these had had any impact on how they understood or coped with their pain.

A repeated concern for me during my first couple of interviews was whether I was gathering information that would allow me to achieve the main aims of the

research. I was aware that often the participants spent considerable time describing their pain and their various attempts to manage and I worried that this information was not relevant to my study. However, by drawing comparisons with the techniques I might use in clinical assessments to build rapport with clients I reasoned that it was important for me to listen to the patients tell their story. I believe that it may not have been possible to probe them on their worries and fears if they felt I was not interested in their pain experience. Moreover, having this information was useful when I later started to do the analysis as it provided a context from which to make sense of the coded data.

Ideas for future research

Further into the process when I had completed several interviews, I was looking at participant files to confirm demographic details when I noticed that the doctors' summary of the consultation did not always match the account I had obtained from the participant. It was beyond the scope of the study to investigate this but it led me to reflect that what the participants had told me was their understanding of the consultation and it would have been shaped by various processes including their memory, how well what they were told fitted with their beliefs, and the doctor-patient relationship.

Research, investigating healthcare practitioner (HPC)-patient communications, frequently looks at the relationship between the attitudes, expectations and beliefs that HPCs and patients bring to consultations and the effects of these on patients (e.g. Friedrikson, 1993). Consistent with my observations of a minority of the participants in my study, it has shown that patients frequently emerge from consultations with a poor understanding of their problems (e.g. Ley, 1988), but

it seems that this research is almost always carried out in primary care rather than secondary care settings. Arguably, patients who have waited a long time for a one off appointment with a specialist are likely to be more anxious which may further impact on patient recall of information.

In particular I started to wonder about the role of language and culture on the consultations. I had noticed that one of the participants who had been especially unhappy with the experience had grown up speaking a different language and in a different culture. Interestingly, I also remember that the only other participant who described the first language as not being English and who did not grow up with British culture had told me that the first time her pain problem was diagnosed and a treatment was prescribed she ignored it because she didn't think it was correct, but after hearing it again from this doctor she had changed her way of thinking about it. This made me curious about the impact of culture and language on the doctor-patient relationship and process of discussing diagnosis and treatment. Having looked into this I have found that research has found that ethnic minority patients or those from lower socio-economic groups are often given less information at consultations and report being less involved the consultations (Cooper & Roter, 2003), but again this research seems to be almost entirely carried in primary care settings.

A number of studies have already investigated the impact of various aspects of chronic pain consultations on outcomes such as adherence to treatment and satisfaction. For example when doctors form collaborative relationships with their patients by providing them with information and involving them in treatment decisions this is associated with better treatment outcomes (for an overview see Stomski, Mackintosh, & Stanley, 2010). However, I would be interested to explore further whether there are differences between patients in terms of how they

understand, make sense of and utilise the information they receive about diagnosis and treatment and whether culture and language influence this.

I would also be interested in exploring whether the understanding of chronic pain that a patient holds prior to consultation influences how s/he receives and makes sense of the diagnosis and treatment plan. Cognitive theory describes a process called assimilation whereby new information is processed in a way that modifies it to fit with an individual's existing schemas, or categories of knowledge (Piaget, 1952). Based on this and observations from my study I would hypothesise that individuals who hold a model of chronic pain which is significantly different to the one that their doctor gives them would need extra input to develop new chronic pain schemas.

Conclusions

This review has summarised my main reflections on my major research project by exploring the process of conducting both the literature review and the empirical paper. Writing it has helped me realise that although there were many points along the way where I felt stuck or overwhelmed, eventually all the issues were resolved. On reflection the majority of the difficulties can either be attributed either to my own lack of confidence in the work or to becoming overly immersed in the detail of one specific area. In both these cases the support of my supervisors helped me re-engage with the bigger picture. I also hope that through highlighting the gaps in the literature and the obstacles in conducting chronic pain research that I encountered, this review may also be of value to others who plan to conduct research in this area.

References

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Appendix 1

Ethics approval letters


National Research Ethics Service
Central London REC 1
Level 7N019, Maternity Block
Northwick Park Hospital
Watford Road
Harrow
Middx
HA1 3UJ
Telephone: 020 8869 3775
Facsimile: 020 8869 5222

06 September 2010

Ms Christine Bonathan
Trainee Clinical Psychologist
Camden and Islington Foundation Trust
Research Dept Clinical,
Education and Health Psychology
Gower St, London
WC1E 6BT

Dear Ms Bonathan

Study Title: Ho do patients understand chronic orofacial pain?
REC reference number: 10/H0718/58

The Research Ethics Committee reviewed the above application at the meeting held on 25 August 2010. Thank you for attending to discuss the study.

Ethical opinion

No ethical issues

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

1. Please omit items 4 & 5 from the consent form.

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Investigator CV		15 July 2010
Protocol	1.2	16 April 2010
CV Jenna Love		15 July 2007
Semi structured interview schedule		
REC application		15 July 2010
Letter of invitation to participant	1	
Participant Information Sheet	1	08 July 2010
Participant Consent Form	1	08 July 2010
Academic Supervisors CV - Amanda Williams		
Evidence of insurance or indemnity		06 November 2009

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H0718/58

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Dr John Keen
Chair

Email: Julie.kidd@mwh.nhs.uk

Enclosures:

*List of names and professions of members who were present at the meeting
and those who submitted written comments
"After ethical review – guidance for researchers"*

Copy to:

*Mr Philip Diamond
UCLH R & D Dept.
1st Floor Maple Court Road
149 Tottenham Court Road
W1T 7NF*



National Research Ethics Service

Central London REC 1
Level 7N019, Maternity Block
Northwick Park Hospital
Watford Road
Harrow
Middx
HA1 3UJ

Telephone: 020 8869 3775
Facsimile: 020 8869 5222

22 September 2010

Ms Christine Bonathan
Trainee Clinical Psychologist
Camden and Islington Foundation Trust
Research Dept Clinical,
Education and Health Psychology
Gower St, London
WC1E 6BT

Dear Ms Bonathan

Full title of study: **Ho do patients understand chronic orofacial pain?**
REC reference number: **10/H0718/58**

Thank you for email and revised consent form dated 27.8.2010. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 25 August 2010. Please note these documents are for information only and have not been reviewed by the committee.

Documents received

The documents received were as follows:

Document	Version	Date
Response to Request for Further Information – Consent form	CB002	25 August 2010

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

10/H0718/58 **Please quote this number on all correspondence**



Yours sincerely

Ms Julie Kidd
Committee Co-ordinator

E-mail: Julie.kidd@nwh.nhs.uk

Appendix 2

Letter of invitation.

University College London Hospitals 	
NHS Foundation Trust	
Facial Pain And Multidisciplinary Service	
	Lead Consultant Consultant Liaison Psychiatrist Consultant Clinical Psychologist Consultant Neurosurgeon Consultant Neurologist Consultant Neurologist Consultant Homeopathic Physician Specialist in Oral Surgery Specialist in Oral Surgery
Unit Secretary:	020 7915 2314/1053
Unit Fax:	020 7915 1105
Patient Enquiries:	020 7915 1057

Date

Version: CB001


Address

I

Dear

Research study on Chronic Orofacial pain


Following your referral to the facial pain clinic I would like to tell you about a research study that is taking place which I hope will be of interest to you.

 Professor Joanna Zaric, Lead Consultant, and Dr Jenna Love, Clinical Psychologist, have identified you as someone who could potentially provide a valuable contribution to our research.

I have enclosed an Information Sheet describing the research and what it would involve. Please take the time to read the sheet carefully. If you would like to take part in the study, please complete the enclosed slip, and return it in the stamped addressed envelope provided, or contact me by telephone or email on the details below.

Yours sincerely

Christine Bonathan
Chief Investigator


Lead Consultant

Supervised by


Dr Jenna Love
Clinical Psychologist
Facial Pain and Multidisciplinary Service



UCL Hospitals is an NHS Trust incorporating the Eastman Dental Hospital, Elizabeth Garrett Anderson & Obstetric Hospital, The Heart Hospital, Hospital for Tropical Diseases, The Middlesex Hospital, National Hospital for Neurology & Neurosurgery, The Royal London Homoeopathic Hospital and University College Hospital.

Appendix 3

Information sheet.



University College London Hospitals

NHS Foundation Trust

Facial Pain And Multidisciplinary Service

Prof. James M. Johnson

Lead Consultant
 Consultant Liaison Psychiatrist
 Consultant Clinical Psychologist
 Consultant Neurosurgeon
 Consultant Neurologist
 Consultant Neurologist
 Consultant Homeopathic Physician
 Specialist in Oral Surgery
 Specialist in Oral Surgery

Unit Secretary: 020 7915 2314/1053
 Unit Fax: 020 7915 1105
 Patient Enquiries: 020 7915 1057

Date: 08.07.10
Version: CB001

Project ID: 10/H0718/58

Patient Information Sheet

Study Title: How do patients understand chronic orofacial pain?

I would like to invite you to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

After reading this information sheet, if you decide you would like to take part, please return the tear off section on the invitation letter or contact me using the details at the end of this sheet.

What is the purpose of the study?

This study aims to explore what beliefs and concerns people with chronic orofacial pain have about the causes of their pain and what it means for their everyday life, both before and after an initial consultation at the Eastman Dental Hospital's Facial Pain Service. A better understanding of these beliefs will help us in assessing patients, managing treatment and in further research.

Why have I been invited?

We would like to speak to a total of 12 patients who are on the waiting list for an assessment at the Facial Pain Service. You have been selected by the Lead Consultant and a Clinical Psychologist at the Facial Pain Service as someone who could potentially provide a valuable contribution to our research, however participation is completely voluntary.

Do I have to take part?


It is up to you to decide. You can read about the study in this information sheet, and you can contact me to discuss it further and ask any questions. I will ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect your treatment in any way.

What will happen to me if I take part?

Taking part in the study will involve 4 elements:

	When	What	Approximate time/ length
1	A few days before your facial pain clinic consultation	An interview with the researcher at UCL University	60 minutes
2	A day after your consultation	Write a letter to the researcher describing your experience of the consultation	1 side of A4
3	A week after your consultation	An interview with the researcher by telephone	15 minutes
4	Before and after your consultation	Complete 2 paper and pencil questionnaires	5 minutes

What will I have to do?

	UCL Hospitals is an NHS Trust incorporating the Eastman Dental Hospital, Elizabeth Garrett Anderson & Obstetric Hospital, The Heart Hospital, Hospital for Tropical Diseases, The Middlesex Hospital, National Hospital for Neurology & Neurosurgery, The Royal London Homoeopathic Hospital and University College Hospital.
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At the first interview I will ask you about your pain. Then, once you've had your consultation at the Facial Pain Service I will ask you to write a brief letter to me describing how you found it. I will also telephone you at home to ask a few more questions about your pain and your consultation. Lastly, the Facial Pain Service will send you 2 questionnaires to complete as part of their assessment. I will ask your permission to look at the results of these and ask you complete them again after your last interview.

The interviews will be audio-recorded so that they can be transcribed for analysis. Once the transcript has been completed, the audio-recording will be destroyed. The transcript will remain confidential, and will contain no information that would enable you to be identified. My supervisors at University College London may read some of the transcript material, but they would not be able to identify you. It is possible that when the study is written up, transcript material may be quoted to enhance the report, but all quotations would be anonymous.

Travel Expenses

Taking part will involve attending UCLH for the first interview. Reasonable travel costs will be reimbursed for this journey. It is important that you provide receipts of your travel/parking where possible.

What are the possible disadvantages of taking part?

I will be asking you about some of the same kinds of things that the doctor will ask you in your initial consultation. Some participants may find it distressing to discuss the effect pain has on their lives, but as a trainee clinical psychologist I have experience in supporting people in such situations. I am also being supervised by a Clinical Psychologist and I can arrange for you to speak to them or another member of the team should you wish to.

What are the possible benefits of taking part?

You may find that the interview is an interesting opportunity to think about what has caused your pain and how this has affected you. The insights that you provide will inform our knowledge of chronic orofacial pain, and we hope that this will help to improve treatment of people with orofacial pain, especially as there is a lack of research in this area.

Can I withdraw from the study?

Your participation in the trial is entirely voluntary. You are free to decline or to withdraw any time without having to give a reason. If you choose not to participate in the study, or to withdraw, this will not affect your future medical care.

What if there is a problem?

Any complaints about the way you have been dealt with during the study or any possible harm you might suffer will be addressed.

Any complaints should be addressed to the Supervisor of this research (Dr Amanda C. de C. Williams, Research Department of Clinical, Educational & Health Psychology, University College London, Gower St, London, WC1E 6BT). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints procedure. Details can be obtained from the hospital.

Will my taking part in this study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. The audio-tape of your interview will be destroyed once the transcript has been completed. The transcript of your interview will be identified by a reference number only and will contain no information that would enable you to be identified. A list of reference numbers linked to personal details to enable us to contact you will be stored securely in a locked cupboard in the Department of Clinical, Educational & Health Psychology at UCL. Transcript material and analysis will be shared with supervisors at UCL for the purposes of training and to ensure the validity of the interpretation. However, none of this material will contain information that would enable you to be identified.

Transcripts will be retained for 5 years after publication of the study, which is normal scientific practice, but will not be used for future studies. Thereafter they will be disposed of securely.

Our procedures for handling, processing, storage and destruction of your transcript are compliant with the Data Protection Act 1998.

The custodian of the data is Dr Amanda C de C Williams, Reader in Clinical Health Psychology, University College London.

What will happen to the results of the research study?

The results of this research will form part of my Doctorate in Clinical Psychology. The intention would also be to publish the results in a peer-reviewed scientific journal. You will have the opportunity to give feedback on the results before they are published. You will also be provided with a summary of the results. It is possible that when the study is written up, transcript material may be quoted to enhance the report. However, your permission would be sought to do so, and all quotations will be anonymous.

Who is organising and funding the research?

This research is being sponsored by the University College London Hospitals. The research is being funded by the Research Department of Clinical, Educational and Health Psychology, University College London.

Who has reviewed the study?

The study has been reviewed by the Central London REC Committee 1.

Further information and contact details

If you would like some further information about the study either return the slip enclosed with the invitation letter or contact me on:

Christine Bonathan (Chief Investigator)
Address: Research Department of Clinical, Educational and Health Psychology
University College London, Gower Street, London, WC1E 6BT
Tel: 07779457429
Email: c.bonathan@ucl.ac.uk

Thank you for reading this sheet.

Appendix 4
Demographic questionnaire.

Participant ID _____

Name _____

Interview date _____

Age _____

Occupation _____

Marital status _____

Ethnicity _____

Duration of chronic pain _____

Pain on other sites _____

Appendix 5

Pre-consultation interview schedule.

- Give information sheet to participant and discuss the interview process
- Check participant has understood the aims and objectives of the interview
- Obtain written consent
- Collect socio demographic data

1. Experience of pain

Please could you describe how you came to be referred to the pain clinic?

Do you have a diagnosis or label?

Can you describe your pain to me in your own words?

- Where is it? And how long have you had it?
- Is it continuous/ intermittent?
- Has it changed over time – intensity/duration of episodes?

Can you tell me about your previous attempts to relieve the pain?

- What have you tried yourself?
- Who have you gone to for help?

2. Understanding of pain

What do you think might have caused your pain in the first instance?

- (try to elicit whether they feel factors such as stress, tissue damage, something they have done, bad luck, accident, ageing etc are involved)
- What was the most important cause?

Why do you think it persists?

What do you see happening in the future with regards to your pain?

- Do you think it will be ongoing?

How has the way you think about your pain changed over time?

What do other people in your life think about your pain – do you agree?

3. Hopes and expectations for consultation

What are your hopes for the consultation?

Do you have any concerns or worries about the consultation?

4. Conclusion

Is there anything else that we haven't talked about that might be important for me to know?

How has the process of thinking and talking about your pain today been for you?

Do you have any other questions?

Appendix 6

Written narrative guidance sheet.

Dear participant,

Please write a brief letter to me (aprox 1 side of A4) following your consultation with the doctor. Please try to write the letter, and either email or post it to me, the day after your consultation with the doctor. This way it will be fresh in your mind.

The letter should describe your experience of the consultation. You can use the following questions as a guide:

- How did you find it?
- What was/ was not useful?
- Did you feel understood?
- Was it similar or different from your expectations?
- Did you learn anything new?
- Do you think it has changed anything for you?
- How did it compare to previous health professionals you have sought help from?

Yours faithfully,

Christine Bonathan
Chief Investigator

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Appendix 7

Post consultation interview schedule.

- Thank participant for their letter

Have your ideas about your pain changed since your consultation? (what is causing it, why it persists etc.)

How will this change the way you go about your day to day life and your management of your pain?

Do you know if you have been given a diagnosis?

What impact has this had?

If there is any change since the last interview – why do you think you have changed the way you think about it?

Appendix 8

Hospital Anxiety and Depression Scale.

HAD Scale

Doctors are aware that emotions play an important part in most illnesses and this questionnaire is designed to help your doctor know how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response. **Tick only one box in each section.**

I feel tense or wound up:

Most of the time
A lot of the time
Time to time, occasionally
Not at all

☐
☐
☒
☐

I still enjoy the things I used to enjoy:

Definitely as much
Not quite so much
Only a little
Hardly at all

☐
☒
☐
☐

I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly
Yes, but not too badly
A little, but it doesn't worry me
Not at all

☐
☐
☒
☐

I can laugh and see the funny side of things:

As much as I always could
Not quite so much now
Definitely not so much now
Not at all

☐
☒
☐
☐

Worrying thoughts go through my mind:

A great deal of the time
A lot of the time
From time to time but not too often
Only occasionally

☐
☐
☒
☐

I feel cheerful

Not at all
Not often
Sometimes
Most of the time

☐
☐
☒
☐

I can sit at ease and feel relaxed:

Definitely
Usually
Not often
Not at all

☐
☒
☐
☐

I feel as if I am slowed down:

Nearly all the time
Very often
Sometimes
Not at all

☐
☐
☒
☐

I get a sort of frightened feeling like "butterflies" in the stomach:

Not at all
Occasionally
Quite often
Very often

☐
☒
☐
☐

I have lost interest in my appearance:

Definitely
I don't take so much care as I should
I may not take quite as much care
I take just as much care as ever

☐
☐
☐
☒

I feel restless as if I have to be on the move:

Very much indeed
Quite a lot
Not very much
Not at all

☐
☐
☐
☒

I look forward with enjoyment to things:

As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

☒
☐
☐
☐

I get sudden feelings of panic:

Very often indeed
Quite often
Not very often
Not at all

☐
☐
☐
☒

I can enjoy a good book or radio or TV programme:

Often
Sometimes
Not often
Very seldom

☒
☐
☐
☐

Appendix 9

Brief Pain Inventory.

BRIEF PAIN INVENTORY

Please circle your response or ask for help if you are having problems

1. Please rate your pain by circling the one number that best describes your pain at its **WORST** in the past week.
 0 1 2 3 4 5 6 7 8 9 10
 NO PAIN PAIN AS BAD AS YOU CAN IMAGINE
2. Please rate your pain by circling the one number that best describes your pain at its **LEAST** in the past week.
 0 1 2 3 4 5 6 7 8 9 10
 NO PAIN PAIN AS BAD AS YOU CAN IMAGINE
3. Please rate your pain by circling the one number that best describes your pain on the **AVERAGE**.
 0 1 2 3 4 5 6 7 8 9 10
 NO PAIN PAIN AS BAD AS YOU CAN IMAGINE
4. Please rate your pain by circling the one number that tells how much pain you have **RIGHT NOW**.
 0 1 2 3 4 5 6 7 8 9 10
 NO PAIN PAIN AS BAD AS YOU CAN IMAGINE
5. Circle the one number that describes how during the past week, **PAIN HAS INTERFERED** with your:
 - A. General activity
 0 1 2 3 4 5 6 7 8 9 10
 DOES NOT INTERFERE COMPLETELY INTERFERES
 - B. Mood
 0 1 2 3 4 5 6 7 8 9 10
 DOES NOT INTERFERE COMPLETELY INTERFERES
 - C. Walking ability
0 1 2 3 4 5 6 7 8 9 10
 DOES NOT INTERFERE COMPLETELY INTERFERES
 - D. Normal work (includes work both outside the home and housework)
0 1 2 3 4 5 6 7 8 9 10
 DOES NOT INTERFERE COMPLETELY INTERFERES
 - E. Relationships with other people
 0 1 2 3 4 5 6 7 8 9 10
 DOES NOT INTERFERE COMPLETELY INTERFERES
 - F. Sleep
 0 1 2 3 4 5 6 7 8 9 10
 DOES NOT INTERFERE COMPLETELY INTERFERES
 - G. Enjoyment of life
 0 1 2 3 4 5 6 7 8 9 10
 DOES NOT INTERFERE COMPLETELY INTERFERES

Appendix 10

Section of Transcript

P: Particularly because I'm learning to live with it, but I do think I can't take ibuprofen every day for the rest of my life, that's just doing horrible things to my organs. I'm going to have to alternate between being on pills, not being on pills. I don't know, I don't want to be like Michael Jackson, forever popping pills. So I'm looking in my mind for a way to make this go away without, I mean in the short term, pills – ok, but without spending the rest of my life popping pills. Yeah, my worse scenario is that it would get a lot worse and stop me living my life.

C: I can of course imagine that is a worse case scenario fear, but there was a time when you really were quite worried that would happen, it would get worse and worse. But now you've got a bit more confidence that it has reached a plateau, but there is a worry...

P: ...about how long this will last for. It could last for years and I don't really want it to.

C: so that is the worry now.

P: there is no doubt that I am looking forward to next week.

C: yes. So what could happen at this consultation allowing you to go out of it feeling that it had been helpful?

P: um, from all the paraphernalia that I've been sent, I'm not expecting miracles, I wasn't expecting miracles anyway, but that made it clear it's a consultation and any sort of treatment that might follow, won't necessarily happen on the day, which is fine. I think that my GPs haven't been very helpful I think because it's beyond their remit. Really what I'm after is some clinical advice on what this is. And if there are ways of managing this, how I can go about doing that. I'm quite happy, I'm aware that I'm the one that has to drive making it better, it can't be anyone else. Um, but equally it could be something like, a rotting jaw, I could have an abscess growing on each side in which case a test would be good. So some sort of checking to make sure that isn't the case as well.

C: ok so to rule out some of these worst case eventualities that are perhaps at the back of your mind. ...

P: ...yeah, I mean it might be that the consultant takes one look at my jaw and says there's no abscess, don't worry. That would be enough, some sort of reassurance from someone whose a consultant and would know about this.

C: So a ruling out of these worst case scenarios, but it's not just about finding a way about managing it, you are wanting some sort of understanding...

P: ... definitely, I want to know what's happening.

C: Why is that so important, what would that change, knowing that?

P: Um, because I don't accept things very well without knowing the background. Um, it came on really quickly for me, it wasn't like a gradual thing and so, it looks like, if it does go, that it will go very gradually, so I just need to see the background to it. I know that I gnash my teeth at night in my sleep I know that. I've been told many times, it's quite loud [laughs] so that might have an impact as well. But if that was the case, what didn't this gradually happen. Why wasn't this over the course of a year or so. Because surely if it was to do with me gnawing my teeth at night then it would have been a gradual wearing away of bits of my bone or something.

C: Some of the theories you might have thought about don't quite seem to fit.

P: Yeah, things don't seem to hang together, and I can't see inside my own body so.... Yeah I guess I'm looking for reassurance and if possible some sort of treatment to make it go away or get better.

Appendix 11

Example of codes grouped into categories.

Categories	Main theme	Sub themes	Codes	Reference and examples
Worry about exacerbation of pain			Worry they are doing things to exacerbate pain	P10:8: 17-19 I'm scared I'm making it worse as well, all the time. When I sneeze or yawn or anything I'm really careful, I don't want to make it worse or do anything to it.
			Fear the cannot control pain at all	P11:1:24-25 I cant keep what I'm doing under control and the power is so strong, its so powerful that it effects this joint, and it also effects the condition of my teeth.
Worry re. diagnosis			Fear of never getting diagnosed and treated	P10:3: 7 It just makes me feel really desperate, like there's never going to be an end to it.
			Worry re limits of technology	P01:7:68-70 They cant check the bruising behind the eyes, can they? There's no real way of doing that
			Worry that will get a 'non diagnosis'	P04:7:4-6 say atypical trigeminal neuralgia, what does that mean? Its probably something you can call anyone with facial pain if you don't know what's going on
		Fear that the pain persists because something curable has been missed	Fear of missing out vital info (when explaining pain to doctors)	P12:3: 22-23 You're frightened to miss something out that might be vital. So I don't know what part of it is important.
			Worry doctors missing something curable	P10:11: 5-8 I deserve, at least somebody to look because it might be that you can fix it. It might be something so simple is just out of line. Might be that 6 weeks down the line, I'm walking around completely normal again
			Worry previous doctor has missed something	P05:2:13-15 And he was amazed actually, he put his hands on my jaw and said open and close it and he said 'I'm amazed nobody has done that to you before'.
Worry re. pain itself	Worry as part of the process of making sense of the pain	Fear that pain signals something even more frightening	Jaw rotting (fear that their jaw is rotting away)	P06:03:44-47 When its around my teeth then it doesn't feel like swelling, its like rotting. I can almost freak myself out by thinking about what it could be. Um, I try not to think about that too much, about what that might actually look like if I was to take away my skin and look at my jaw. That does freak me out a bit.
			Fear that there may be abscesses	P06:4:28 I could have an abscess growing on either side

			Fear it could be a symptom of MS	P08:3: 15-17 Also because that pain can also be linked with other conditions like MS so suppose its an early indicator of MS. I don't know whether that's brain thing that the MRI can say if its not MS. But there is kind of extra worry on top of it as well.
			Worried their teeth are wearing away to nothing	P11:3:46-50 I am really afraid because my teeth are getting more and more worn out and this problem really its difficult for me when I think that these teeth might not be useful for me for a long and I've never had problems with teeth, with fillings and these types of things. Everything was done on time and now I started losing them. I could continue destroying them.
			Worry they are imagining it	P06:6:22-23 That is difficult, how do I know I'm not making it up? I don't know, maybe I'm making it up. There is no visible evidence of what is going on here.
Worries re. what others think or do			Fear of being touched	P02:2:44-46 I don't go in crowds when I can avoid it because I'm frightened of people coming close to me. I don't like anyone getting close to me because of the pain.
			Worry others will think badly of them	P02:1: 69-71 We say that because a lot of people think that...[its because of a] drunken brawl
Worry re. implications of pain			Worry that pain is making them weak	P10:10:15-17 Yeah, I'm the least emotional person, I'm really, really tough and I'm always the person that will hold everyone else up and I never get emotional. Never cry at anything on TV
			Worry that pain is exhausting them	P10:8: 1-3 I do feel physically weaker all the time. I think the pain just makes you feel really weak, I feel its zapped me, I'm really tired
			Worry impact on others	P02:4: 72-73 when I have a bad day I have a real bad day and its not fair on people close to me.
Worry re. future			Worry that the pain is aging them	P01: 6: 64 I think aging, its sort of physically aging me quicker than it would do normally
			Longer pain lasts more worrying it gets	P10:8: 39-40 If it was something straight forward they would have found it
			Fear of pain getting worse over time	P02:5:71 I suppose the worst fear is that the pain will get worse and worse
			Fear of pain stopping me living my life	P06:4:6-7 my worse scenario is that it would get a lot worse and stop me living my life.

